THE UNIVERSITY *of* EDINBURGH

Resilience factors in parents of children with an intellectual disability: hope and locus of control

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Doctorate in Clinical Psychology

The University of Edinburgh

August 2015

"Hope is easy for every fool but hard for the wise one. Everybody can lose himself in foolish hopes, but genuine hope is something rare and great."

Paul Tillich (1990)

D. Clin. Psychol. Declaration of own work

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Acknowledgements

Firstly I would like to thank the parents who took part in my study for giving up their hard earned time. I would like to thank my supervisors Dr Hannah MacLean, Dr Kenneth McMahon, Dr Dougal Hare and Dr Karen McKenzie, for their support, advice and encouragement throughout this process.

I am very grateful to all my friends and family for supporting me from the very start and reminding me there is an end. Thank you to my mum and dad, for all the phone calls, food, banana discussions and encouragement. Thank you for being there for the challenges of this project and supporting me in all I undertake. Thank you to my home girls for your prayers, texts, cards and questions. Katrina, thank you for my thesis survival kit without which I would not have made it. Thank you Flip, for being with me on the journey, which was the positive thing I couldn't remember. Alice, coffee is always a good idea but you taught me that croissants make it better. Thank you for being with me and normalising the time spent in the PhD lab! Thank you Shauneen for taking me under your wing in first year and being my friend ever since. Thank you Ailsa for keeping me right and my tea warm. And thank you to my entire cohort for your support, advice, laughter and fun over the last three years.

I dedicate this thesis to my grandmother Clara, who encouraged me to pursue challenges and to work hard for what I wanted. But most importantly she instilled in me a belief of possibility and hope.

Portfolio Thesis Overview

The portfolio thesis was designed to support the development of research competencies required for practicing clinical psychologists. The portfolio consists of an overall thesis abstract and two thesis chapters: a systematic review and empirical paper. This constitutes part fulfilment of the degree of Doctorate in Clinical Psychology at the University of Edinburgh. The remaining components included two case conceptualisations, a thesis proposal and a small scale research project in combination with six clinical placements over three years.

The references from the document as a whole are included in the 'Portfolio Thesis References' section and are written following the British Psychological Society's style guide (BPS, 2015). The references within chapters are written within the specifications of the author guidance from the specified journal.

Portfolio Thesis Abstract

Aims

There is an increasing focus on factors associated with resilience in parents of children with disabilities. Two such resilience factors are hope and locus of control. This thesis aimed to review the existing literature on hope and its relationship to psychological outcomes, in parents of children who have a disability. A research study aimed to explore relationships between two resilience factors, hope and locus of control, and their links with knowledge of behavioural principles and challenging behaviour.

Methods

To address the first aim, a systematic review of the literature was conducted for hope (operationalised using Snyder's model of hope). Nine online databases were systematically searched using a set of pre-defined criteria. Eligible papers were rated for quality using an established tool (SIGN, 2008) adapted for this review. Secondly, a cross-sectional research study sampled mothers of children with an intellectual disability (N=32) who completed four self-report measures online: State Hope for the Child Scale (based on the State Hope Scale), Parental Locus of Control Scale (child control and parental control subscales), Behavior Problems Inventory for Individuals with Intellectual Disabilities – Short Form, and the Knowledge of Behavioural Principles Questionnaire (KBPQ), which was developed for the study.

Results

The systematic review identified 11 papers; three were rated as good quality, seven rated as fair quality and one rated as poor. Studies included participants whose children had a range of disabilities. Participants in the following groups were over-represented: white, middle to high socio-economic status mothers, educated to college or graduate degree level and who self-selected to participate. For all studies, mean hope was higher than the median value for each scale used,

suggesting the presence of hope in most parents. Hope was positively associated with a range of variables, such as, quality of life, and negatively associated others, including stress. There were differences in the interactions between hope components of agency and pathways, and psychological variables. There were also differences between how maternal and paternal hope related to psychological variables.

The characteristics of those recruited to the research study mirrored those found in previous research. The majority of participants were married/cohabiting mothers, living in areas of higher socio-economic status, and caring for a child with a moderate or severe ID. In addition, there was a higher incidence of children with autism spectrum disorder in this sample. Mothers reported feeling hopeful, although they experienced a range of challenging behaviours (mean 14.6 behaviours per child). Due to poor psychometric properties of the KBPQ, data was not included in the analysis; however, some areas of strength and weakness in knowledge were evident. Correlational analysis showed that higher levels of resilience factors were associated with lower levels of self-injurious and aggressive/destructive behaviour. Stereotyped behaviour was not associated with either hope or locus of control. In contrast to previous research, higher hope was associated with a more external locus of control for the child control subscale.

Conclusions and implications

Hope is an established resilience factor in the general population. Findings from both the systematic review and research study suggest that hope is present in parents and caregivers of children with a disability. The systematic review demonstrated consistent adaptive relationships between hope and psychological variables. This highlights hope's role as a resilience factor in parents of children with a disability. The research study added to the literature on how maternal hope and locus of control inter-relate in this population. Generalisability of study results was limited by sample size, population characteristics and by scales used. However, overall findings suggest that it would be beneficial to consider resilience factors

when planning and evaluating interventions and research. Furthermore, examining specific aetiologies of disability, such as ASD, might also clarify whether these affect the relationships between hope and other psychological variables.

Keywords: hope, locus of control, parent, intellectual, developmental, disability

Chapter 1: Systematic Review

This chapter presents a systematic review of the literature investigating the presentation of hope in parents of children with disabilities and its relationship to other psychological variables. It is formatted for submission to the journal 'Research in Developmental Disabilities' including the referencing format of the American Psychological Association, Sixth Edition (2010). Author guidelines are contained in Appendix A. A structured abstract is followed by an introduction to the objectives of the work and background literature. A methods section maps out the search strategy and selection criteria. Results are based on a critical appraisal through quality criteria evaluation. A discussion of the clinical and research implications based on the evidence presented concludes the review.

How does hope present in parents of children with a disability? A systematic review

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Abstract

Background

There is an increasing focus on factors associated with resilience in parents of children with disabilities. The concept of hope has positive associations in the general population, identifying it as a potential contributor to resilience in parents of children with disabilities.

Objectives

This review systematically examined the existing literature exploring hope, operationalised using Snyder's theory of hope, in parents of children with disabilities. It aimed to describe how hope presents in parents and focused on the relationship between hope and psychological variables to inform clinical practice and future research.

Method

Peer-reviewed English language studies that examined parents or caregivers of children with a physical, developmental or intellectual disability, that measured hope following Snyder's model and that included at least one parental psychological outcome were considered for review. Online database searches (PsyInfo, Medline and Embase/Embase classic, CINAHLplus, ERIC, ASSIA, Sociological Abstracts, Social Services Abstracts and PubMed) and hand searches of two journals in the field were carried out. Study quality was rated using pre-defined criteria adapted from an established rating tool (SIGN, 2008).

Results

From 174 studies, 11 papers met eligibility criteria. Three papers were rated as good quality, a further seven rated as fair quality and one rated as poor. Studies investigated 1789 caregivers of children with a range of disabilities including fragile X syndrome, autism spectrum disorder and Down syndrome. Studies were biased to participants who were white, middle to high socio-economic status mothers, who

were educated to college or graduate degree level and who self-selected to take part. Seven studies used the Trait Hope Scale and three studies the State Hope Scale. For all studies, mean hope was higher than the median value for each scale used, suggesting the presence of hope in most parents. Hope was positively associated with a range of adaptive psychological variables, e.g. quality of life, and negatively associated with less adaptive variables, e.g. stress. The two components of hope (agency and pathways) varied in their relationship to psychological variables. There were also differences between how maternal and paternal hope related to psychological variables.

Conclusions

Hope is present in parents and caregivers of children with a disability. Hope had significant relationships with a range of psychological variables in line with previous research from the general adult population. This highlights hope as a potential resilience factor within parents of children with disabilities, which has both clinical and research implications.

Highlights

- Hope was positively associated with quality of life, family adaptability, happiness and positive affect.
- Hope was negatively associated with stress, anxiety, worry and depression.
- Findings were limited by low number of studies, poor quality of reporting and lack of comparison or control groups.
- Most studies only included mothers.
- Measurement of hope was inconsistent across studies.

Key words: hope, disability, parent, psychological variables

1. Introduction

1.1 Background

The psychological distress experienced by parents of children with an intellectual disability (ID) is well documented in research literature (e.g. Baker, Blacher, Crnic & Edelbrock, 2002) and highlighted as a focus for change in government policy (Department for Children, Schools & Families, 2008; The Scottish Government, 2013). Parents of children with various additional needs, e.g. physical disability or chronic life-limiting illness, demonstrate a similar pattern of increased distress and lower well-being (Cousino & Hazen, 2013). However, parents also report positive experiences (Hastings & Taunt, 2002) and show resilience to cope with the complex challenges of parenting a child with a disability (Peer & Hillman, 2014). Growing interest in these characteristics reflects a wider trend of positive psychology to identify strengths and abilities rather than weaknesses (Hastings & Taunt, 2002). This trend is evidenced by the increasing literature focused on adaptations to the caring role and facets of positive psychology such as resilience (Horsley & Oliver, 2013) and their potential to guide approaches to intervention (Seccombe, 2002). Positive parental cognitions such as optimism, hope and possessing a positive outlook may support parents to perceive challenging situations as more manageable, mediating the effects of stress (McDonald, Poertner & Pierpont, 1999).

Hope is an established protective factor from distress in adults (Snyder, 2002) and could be clinically used as a diagnostic and therapeutic tool (Snyder, 1995). The model of hope proposed by Snyder and colleagues (Snyder, 1995; 2002; Snyder et al., 1991) is the most dominant and researched hope conceptualisation in the past twenty years (Feldman & Kubota, 2015; Rand & Cheavens, 2009). Other models of hope differ in their theoretical basis, and their measurement tools often include a range of other resilience factors (e.g. optimism in Millar & Power, 1988). Following an initial examination of the literature, Snyder's model was chosen as the focus of this review since there is a sufficient body of literature to draw conclusions from, in

comparison to other conceptualisations of hope, where there are fewer studies to draw upon. Therefore, this review begins by outlining Snyder's theory of hope (Snyder, 1995; 2002; Snyder et al., 1991) and the recognised associations of hope in the general population. The existing literature investigating hope in parents of children with disabilities will then be systematically examined, and the results summarised.

1.2 Snyder's theory of hope: the will and the ways

Prior to the publication of Snyder et al.'s (1991) paper, hope was often perceived as a view that one's goals could be met (e.g. Stotland, 1969). This postulates that an individual and their behaviour are goal driven; therefore, hope was the view of likely goal attainment. Snyder and colleagues hypothesised that hope was a more complex cognitive appraisal of one's relationship to goals made up of two components, the 'will and the ways' (Snyder, 1995; 2002; Snyder et al., 1991; Snyder et al., 1996). The will or '*agency*' component is a resolve that goals will be successfully met in the past, present and future. This sense of agency was referred to as 'goal-direct determination'. It encapsulates the perceived ability and motivation to both initiate and maintain actions needed to achieve the goal. The ways or '*pathways*' component is the perceived ability to generate successful plans or routes to meet goals. Thus, hope is viewed as a process of cognitive appraisal, constructed of the perceived sense of successful agency (goal-directed action) and pathways (plans to meet goals).

These components, although positively related and reciprocal, were seen as two distinct cognitional appraisals; therefore individuals could vary on each aspect (Snyder et al., 1991). The necessity of both components and their independence was supported by confirmatory factor analysis (Babyak, Snyder & Yoshinobu, 1993). Snyder emphasised hope as an egocentric "cognitive set" but acknowledged that experience and external factors influenced our assessment of agency and pathways (Snyder, 2002). Consequently, hope is not a state of goal-orientated thinking but a subjective and enduring dispositional evaluation of agency and pathways,

consistent across environments. Thus, an individual's level of hope lies on a continuum and differs between individuals as varying degrees of hope (Snyder et al., 1991).

Snyder (2000) purports that hope was different from other dispositional resilience factors such as optimism. Optimism refers to a general expectancy that favourable outcomes will occur rather than unfavourable outcomes (Scheier & Carver, 1985). Although still positively framed, hope has an 'active' component, separating it from optimism's simple expectations (Peterson & Seligman, 2004).

1.3 Measurement of hope

Although hope has been discussed as a dispositional variable, it can be measured at this 'trait' level (Trait Hope Scale, *THS*; Snyder et al., 1991) or at a more situational level (State Hope Scale, *SHS*; Snyder et al., 1996). As a dispositional variable, a person's hope agency and pathways thinking are assumed to be relatively consistent. However, a person's hope can fluctuate within a situation and can, therefore, be measured as a current 'state'. In Snyder et al.'s (1991) original article, the THS consisted of twelve items rated from one (definitely false) to four (definitely true). Four items assessed pathways, four items assessed agency and four were filler items.

Snyder et al. (1996) postulated that a state measurement would increase understanding of hope affected by more proximal events and provide a 'snapshot' of current goal-directed thinking. The SHS consists of three agency and three pathway items from the THS (filler items were omitted). The measure directs respondents to focus on the 'here and now' and rate items to reflect their thinking in the moment. Statements were rated from one (definitely false) to eight (definitely true). Snyder et al. (1996) also reported rating the THS from one to eight, differing from the original paper (Snyder et al., 1991).

1.4 Hope in the general population

High hope is associated with general positive outcomes, better psychological health and physical well-being, successful problem-solving and increased life satisfaction (Chang, 1998; 2003; Shorey, Little, Snyder, Kluck & Robitschek, 2007). Individuals with higher hope identify more goals, show resilience and problem solved new routes to goal attainment when faced with blockages (Snyder et al., 1991). Higher hope is associated with using adaptive coping strategies (Snyder, 2000; 2002), particularly coping better with ongoing distress (Barnum, Snyder, Rapoff, Mani & Thompson, 1998). This is relevant to parents of children with developmental disabilities whose behavioural problems can persevere, thereby presenting ongoing challenges (Murphy et al., 2005).

Furthermore, individuals identified as possessing high hope also report more positive emotional experiences and view barriers to success as challenges not stressors (Oettingen & Gollwitzer, 2002). Conversely, low hope is associated with lower confidence and a lower success rate in goal attainment (Robitsheck, 1996). When combined with other maladaptive mechanisms, e.g. immature defence style, low hope can lead to high levels of dysphoria (Kwon, 2000). More specific mental health variables have also been investigated. Lower levels of anxiety and depression were associated with higher hope (Chang, 2003; Chang & DeSimone, 2001; Snyder, 2000; 2002). Recently this evidence has been used to trial hope-based interventions in a student population, with successful outcomes in both traditional multi-session interventions (Cheavens, Feldman, Gum, Michael & Snyder, 2006) and single session formats (Feldman & Dreher, 2012).

1.5 Rationale for systematic review

Evidence of other parental cognitions or resilience factors in parents of children with disabilities has been reviewed (Hassall & Rose, 2005); however, there has been no systemic review focused on hope. Qualitative research with parents of children with disabilities has found hope to be a “dynamic process” that supported parents

to re-evaluate family life (Kausar, Jevne & Sobsey, 2003). Parents of children with developmental disabilities reported that a message of "no hope" was often imposed on them by professionals and if parents expressed hope, it was interpreted as a maladaptive behaviour (Kearney & Griffin, 2001). Therefore, clinicians need to understand how hope typically presents in this population, whether it is an adaptive resource and how it interacts with psychological variables (Peer & Hillman, 2014).

Hope is an established paradigm and tool in similar complex populations, e.g. parents caring for a child with a serious illness (Reder & Serwint, 2009). In children who exhibit externalising behaviour problems, hope related to key parenting abilities such as having a warmer more nurturing parenting style, using more adaptive coping and being able to develop a more cohesive active family environment (Kashdan et al., 2002).

Parents of children with disabilities manage a range of challenging tasks to care for their child (Baker-Ericzn, Brookman-Frazee, & Stahmer, 2005). They therefore need the motivation and strategies to be able to achieve these tasks, equivalent to Snyder's cognitive set of agency and pathways (Snyder, 2002; Snyder et al., 1991). The established associations of hope in the adult population are highly relevant for parents of children with disabilities, who consistently struggle with stress and negative psychological variables (Hassall, Rose & McDonald, 2005). When faced with a crisis or with challenging behaviour, parents need to draw on their problem-solving skills and remain resilient, identifying hope as a theoretically important variable to consider (Watson & Hayes, 2011).

1.6 Review aims

The primary purpose of this review was to identify and critically evaluate, using a set of quality criteria, the current research literature on hope, within Snyder's framework (Snyder, 2002; Snyder et al., 1991), in parents of children with a disability. Findings will be summarised, including information regarding participant

characteristics and parental psychological variables that are associated with hope. Findings from the literature will be considered in relation to clinical practice, with gaps in the available literature highlighted.

2. Methods

2.1 Protocol

A review protocol was designed following guidance for undertaking reviews in health care (Centre for Reviews and Dissemination, CRD, 2009). It outlined the review question and inclusion criteria (Participants, Interventions, Comparisons, Outcomes, and Study Design, PICOS) with predefined strategies for searching, data extraction, quality assessment and data synthesis (Appendix B).

2.2 Eligibility criteria

All relevant published studies in English-language, peer-reviewed journals were considered (Table 1). Studies were included if they sampled parents or caregivers of children (aged up to and including 18 years old) who have a disability (physical, intellectual or developmental) and investigated hope within the framework of Snyder's theory of hope. Intervention studies, where baseline data on hope was available, were also included by requesting data from the main author contact cited in the paper. Additionally, studies were required to measure at least one parental psychological or well-being variable, e.g. parental stress, adjustment, depression or anxiety. Qualitative studies, conference proceedings and published dissertations were excluded. Studies where the abstract or paper was unavailable were also excluded.

Table 1

Eligibility criteria for study selection for final review

Inclusion Criteria	Exclusion Criteria
• Participants were parents or caregivers of children (≤18 years old) with a disability (physical, developmental or intellectual) • Hope was measured within the framework of Snyder's Theory of Hope • At least one parental psychological or well-being outcome was measured • Controlled, quasi-experimental, small-N, case study, cohort, mixed methods, intervention or observational study designs • English-language studies published in peer review journals • Studies published on or before 07.12.14	• Conference proceedings, published dissertations and other non-peer reviewed literature • Qualitative studies • Abstract or full text unavailable • Review papers

2.3 Information sources

Online searches were conducted using Ovid (PsyInfo, Medline and Embase/Embase classic), EBSCO (CINAHLplus and ERIC), ProQuest (ASSIA, Sociological Abstracts, and Social Services Abstracts) and PubMed databases. All publication years were included up to 7th December 2014. Search terms covered variations of hope, parent and disability (Table 2), and were used in both subject heading and key word searches. A hand search was conducted of the most frequently cited journals in the database search (Journal of Intellectual Disability Research and British Journal of Learning Disabilities). Reference lists of review papers were searched for additional articles that met inclusion criteria.

Table 2

Search terms used in online database search

	Search terms
Hope	Hope, hope theory
Parent	Parent, parents, parental, parent*, mother*, maternal, father*, paternal, caregiver, carer, care*
Disability	Child disabled, developmental delay, developmental disabilities, developmental disability, developmental disorders, intellectual disabilities, disabilities, disabled persons, disabl*, intellectual disability, intellectually disabled, intellectual impairment, learning disabilities, learning disability, learning difficulties, learning disorders, mental retardation, mentally retarded, mental* handicap*, mental deficiency, mentally disabled persons, multiple disabilities, neurodevelopment disorders, pervasive developmental disorders

*truncation symbol

2.4 Study selection

Titles and abstracts of studies identified through searching were screened with reference to eligibility criteria. Where there was insufficient detail in the abstract, full-text articles were sought and screened for criteria. Those meeting eligibility criteria were included for final selection and methodological appraisal. Figure 1 outlines the systematic review study selection following the PRISMA statement (Moher, Liberati, Tetzlaff, & Altman, 2010).

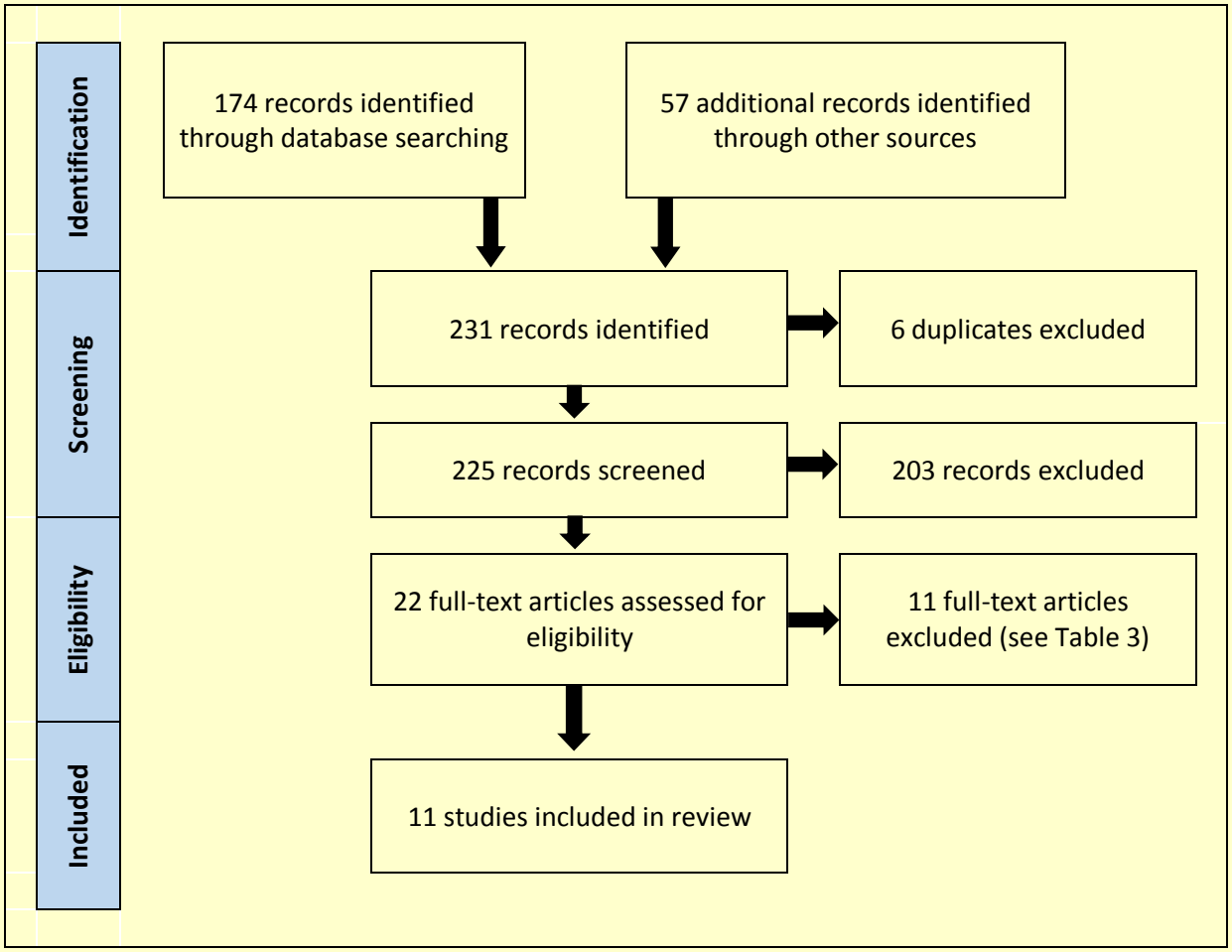

Figure 1 PRISMA flow diagram of systematic identification of articles included in final review

2.5 Data collection process

Data collection and extraction were completed for all studies included in the final selection. Following guidance on systematic reviews (CRD, 2009), data was synthesised on: general information, study characteristics, participant characteristics and setting and psychological variables data/results. A data extraction form was used to facilitate this (Appendix C).

2.6 Quality appraisal

Assessment of methodological quality and risk of bias was appraised using published quality guidance (Scottish Intercollegiate Guidelines Network, SIGN, 2008), adapted to meet the specific review area (Appendix D) following recommendations from CRD guidance (2009). Adaptations were made to ensure adequate appraisal of studies with a cross-sectional design, and to focus on

relevant quality characteristics, such as, recruitment methodology. Eleven quality criteria were rated across six domains: research question, selection of participants, assessment, confounding variables, statistical analysis, and quality of reporting. Criteria were rated as: well-covered (3), adequately addressed (2), poorly addressed (1), not addressed (when not mentioned or aspect of study design was ignored, 0, SIGN, 2008). Total scores calculated for each study (max. 33) were converted into percentages, categorised as: good (≥ 75%), fair (74–50%) or poor (≤ 50%; CRD, 2009).

A second rater independently rated five (45%) of the studies selected for final review. Excellent inter-rater consistency was found (intraclass correlation co-efficient r=.843, p<.001; Cicchetti, 2001). Disagreements between ratings were reconciled through discussion.

3. Results

3.1 Excluded studies

A total of 174 studies were identified through search strategies (Figure 1). A common reason for exclusion at screening was articles that included adults with intellectual disabilities due to the search terms used. The word 'hope' was also frequently used by authors as a descriptor or opinion, but unrelated to the construct investigated by this review. Table 3 details reasons for exclusion of those studies where full text was retrieved, but which were excluded from the review.

Table 3

Summary of excluded studies at full-text review

Reason for exclusion
Participants were parents of children with specific educational learning 'difficulties' rather than a global disability (i.e. children's IQ was within the average range)
• Al-Yagon, M. (2007). Socioemotional and Behavioral Adjustment among School-Age Children with Learning Disabilities The Moderating Role of Maternal Personal Resources. The Journal of Special Education, 40(4), 205–217.
Hope not measured within the framework of with Snyder's theory
• Dagenais, L., Hall, N., Majnemer, A., Birnbaum, R., Dumas, F., Gosselin, J., ... & Shevell, M. I. (2006). Communicating a diagnosis of cerebral palsy: caregiver satisfaction and stress. Paediatric neurology, 35(6), 408-414.
• Juvonen, J., & Leskinen, M. (1994). The function of onset and offset responsibility perceptions in fathers' and mothers' adjustment to their child's developmental disability. Journal of Social Behavior & Personality, 9(5), 1994, 349-368.
• Padencheri, S., & Russell, P. S. (2002). Challenging Behaviours among Children with Intellectual Disability The Hope Busters? Journal of Intellectual Disabilities, 6(3), 253-261.
• Wong, M. G., & Heriot, S. A. (2007). Vicarious futurity in autism and childhood dementia. Journal of autism and developmental disorders, 37(10), 1833-1841.
• Wong, M. G., & Heriot, S. A. (2008). Parents of children with cystic fibrosis: how they hope, cope and despair. Child: care, health and development, 34(3), 344-354.
Intervention study where baseline data not available from the author
• Farber, M. L., & Maharaj, R. (2005). Empowering high-risk families of children with disabilities. Research on social work practice, 15(6), 501-515.
No physical, developmental or intellectual disability described
• Mednick, L., Cogen, F., Henderson, C., Rohrbeck, C. A., Kitessa, D., & Streisand, R. (2007). Hope more, worry less: Hope as a potential resilience factor in mothers of very young children with type 1 diabetes. Children's Healthcare, 36(4), 385-396.
Parental hope not measured
• Al-Yagon, M. (2009). Comorbid LD and ADHD in childhood: socioemotional and behavioural adjustment and parents' positive and negative affect. European Journal of Special Needs Education, 24(4), 371-391.
• Ruiz-Robledillo, N., De Andrés-García, S., Pérez-Blasco, J., González-Bono, E., & Moya-Albiol, L. (2014). Highly resilient coping entails better perceived health, high social support and low morning cortisol levels in parents of children with autism spectrum disorder. Research in developmental disabilities, 35(3), 686-695.
• Nachshen, J. S., & Minnes, P. (2005). Empowerment in parents of school-aged children with and without developmental disabilities. Journal of Intellectual Disability Research, 49(12), 889-904.

3.2 Included studies

Eleven studies (see Table 4) met eligibility criteria, investigating hope across five countries from 2001–2013 (Al-Yagon & Margalit, 2009; Bailey Jr, Sideris, Roberts & Hatton, 2008; Baldry, Bratel, Dunsire & Durrant, 2005; Einav, Levi & Margalit, 2012; Faso, Neal-Beevers & Carlson, 2013; Horton & Wallander, 2001; Lloyd & Hasting, 2009; Ogston, Mackintosh & Myers, 2011; Truitt , Biesecker, Capone, Bailey & Erby, 2012; Watson, Hayes, Radford-Paz & Coons, 2013; Wheeler, Skinner & Bailey, 2008). The total number of participants across studies was N=1779 (1601 mothers, 126 fathers, 62 other caregivers). Children's disabilities included: fragile X syndrome (FXS), chronic physical health conditions (spina-bifida, cerebral palsy and insulin dependent diabetes), autism spectrum disorder (ASD), Down syndrome, intellectual disabilities, foetal alcohol spectrum disorder (FASD), developmental delay and developmental disabilities.

Baldry et al.'s (2005) study involved an intervention. The corresponding author was contacted and baseline data obtained. A cross-sectional design was adopted by the remaining ten studies for quantitative data. Two studies used mixed methodologies (Watson et al., 2013; Wheeler et al., 2008); however, the qualitative aspect of these studies was not examined. The most frequent parental psychological outcome investigated was parental stress as measured by: the Parenting Stress Index, the Parents of Children with Disabilities Inventory, and the Questionnaire on Resources and Stress Friedrich's short-form. Parental worry, mood, happiness, optimism and anger were also investigated. More systemic family characteristics were measured including perceived family support, quality of life, sense of coherence (SOC), coping and family adaptability. Four studies included child variables such as severity of autistic symptoms, problem behaviours or level of disability.

3.3 Methodological quality and risk of bias across studies

Study quality ratings for domain scores, total scores and overall quality rating are summarised in Table 5. Median quality rating was 66.7% (fair). Interpretation of study results was guided by quality ratings. Three studies were rated as good and

seven studies were rated in the fair category; these 10 were retained for narrative synthesis of results. One paper (Watson et al., 2013) was rated as poor, with particularly low quality ratings for selection of participants, and was therefore excluded. Across studies, quality of reporting and clarity of selection of participants received the lowest ratings (median quality 50% and 60% respectively).

Table 4

Study characteristics of eligible papers

Study (year) Country [#]	Study Design, Data Collection Methodology	Statistical Analysis	Participant Characteristics & Sampling	Outcome Measures	Significant findings in relation to Hope
Al-Yagon & Margalit (2009), Israel [1]	Cross-sectional, questionnaires administered by research assistant at a centre for mentally and physically disabled children	ANOVA, hierarchical regression	N=199 mothers of infants with developmental disabilities in an early intervention programme (N=95) or respite (N=104) recruited from the centre	THS, Parenting Stress Index – Short Form, Affect Scale, Coping Scale, Sense of Coherence Scale (SOC), Family Adaptability and Cohesion Evaluation	• There was no difference in level of hope between early intervention and respite groups. • There was no difference in hope between mothers of children with Down syndrome compared to other types of ID. • Hope predicted positive affect but not negative affect.
Bailey et al. (2008), USA [2]	Cross-sectional, questionnaires posted to family	Correlation, t-test	N=108 mothers of children with FXS, enrolled in a longitudinal study of family adaptation to FXS	SHS, Parenting Stress Index, State Anxiety Scale, Beck Depression Inventory-II, Quality of Life Inventory, Trait Anger, Expression Inventory-2, Life Orientation Test-Revised, Child Behavior Checklist, Vineland Adaptive Behavior Scales	• Hope data was negatively skewed (mothers expressed higher levels of hope) • Hope was correlated positively with optimism and quality of life. • Hope correlated negatively with stress, depression, anxiety and anger. • No difference found between mothers of children with gene permutation FXS and mothers of children with full mutation FXS. • Hope was not associated with child adaptive behaviour or behaviour problems.

SHS State Hope Scale, *THS* Trait Hope Scale, *FXS* Fragile X syndrome

Study (year) Country [#]	Study Design, Data Collection Methodology	Statistical Analysis	Participant Characteristics & Sampling	Outcome Measures	Significant findings in relation to Hope
Baldry et al. (2005), Australia [3]	Intervention, mixed methodology, paper questionnaires administered by researcher	Correlation, MANOVA	N=69 (N=59 data available) family members (parents, grandparents and siblings) referred to family support service for children with a disability whose placement is at risk, recruited through support workers	SHS, The Happiness Measures	• Hope in primary carers increased significantly from pre-intervention to post-intervention. • Hope at six months in primary carers post-intervention continued to increase but did not meet adjusted significance level. • Pre-intervention hope was positively associated with pre-intervention happiness in all caregivers*. • Post-intervention hope was positively associated with post-intervention happiness in primary caregivers.
Einav et al. (2012), Israel [4]	Cross-sectional, questionnaires administered by research assistant at a centre for mentally and physically disabled children	Correlation, structural equation modelling	N=111 mothers of children with developmental delay and disabilities (Down syndrome N=83, developmental delay N=21, other syndromes N=7) recruited from the centre	THS, Sense of Coherence Scale, The Family Adaptability and Cohesion Evaluation Scale, Coping Scale	• Hope was positively associated with sense of coherence, family cohesion and coping. • Sense of coherence and coping strategies directly predicted hope (mothers with high levels of sense of coherence and high coping strategies, felt more hopeful). • The effect of cohesion on hope was mediated by sense of coherence. The effect of adaptability on hope was mediated by coping.

SHS State Hope Scale, *THS* Trait Hope Scale, *SOC* Sense of coherence, *data provided by study author, subsequent analysis conducted for this study (data on other measures used in the study not provided: Family Empowerment Scale, Parent-Child Relationship Inventory, Child Abuse Potential Inventory, McMaster Family Assessment Device, Working Alliance Inventory)

Study (year), Country [#]	Study Design, Data Collection Methodology	Statistical Analysis	Participant Characteristics & Sampling	Outcome Measures	Significant findings in relation to Hope
Faso et al. (2013), USA [5]	Cross-sectional, online survey completed independently	Correlation, ANOVA, hierarchical linear regression	N=71 parents (N=53 mothers, N=18 fathers) of children with ASD recruited from University of Texas Autism Project via email (Listserv)	THS, Vicarious Futurity Scale, Parenting Stress Index-Short Form, Center for Epidemiologic Studies Depression Scale, The Satisfaction With Life Scale, Gilliam Autism Rating Scale 2nd Edition	• There was no significant difference between levels of agency and pathways between mothers and fathers. • Maternal agency was positively correlated with vicarious hope and life satisfaction. • Maternal agency was negatively correlated with depression and autism symptom severity. • Maternal pathways was positively correlated with vicarious hope. • Maternal pathways was negatively correlated with depression. • Paternal agency was positively correlated with life satisfaction. • Paternal agency was negatively correlated with depression and parenting stress. • Paternal pathways was positively correlated with life satisfaction and autism symptom severity. • Paternal pathways was negatively correlated with depression and parenting stress. • Parental agency predicted life satisfaction and depressive symptoms.

THS Trait Hope Scale, *ASD* Autism spectrum disorder

Study (year), Country [#]	Study Design, Data Collection Methodology	Statistical Analysis	Participant Characteristics & Sampling	Outcome Measures	Significant findings in relation to Hope
Horton & Wallander (2001), USA [6]	Cross-sectional, questionnaires given at clinic appointments and returned by post	Correlation, hierarchical multiple regression	N=111 mothers of children with cerebral palsy (N=32), spina-bifida (N=33), or insulin dependent children (N=46) contacted at scheduled clinic appointment	THS, Parents of Children with Disabilities Inventory, Brief Symptoms Inventory, Social Support Questionnaire-6, Parents of Children with Disabilities Inventory	• Hope was not normally distributed. • Hope correlated positively with social support satisfaction. • Hope correlated negatively with maternal distress and disability-related stress. • Mothers of children with diabetes reported higher levels of hope compared to mothers of children with spina-bifida group. • Hope predicted distress and moderated the role of disability-related stress (for a high level of stress, high hope mothers reported less distress than low hope mothers).

THS Trait Hope Scale

Study (year), Country [#]	Study Design, Data Collection Methodology	Statistical Analysis	Participant Characteristics & Sampling	Outcome Measures	Significant findings in relation to Hope
Lloyd & Hasting (2009), UK [7]	Cross-sectional, questionnaires sent and returned by post	Correlation, hierarchical linear regression	N=196 parents (N=138 mothers, N=58 fathers) of children with ID (autism N=56, Down syndrome N= 26, cerebral palsy N= 16, N=40 unspecified/mixed aetiology), recruited through schools for children with ID in Wales and England	THS, Parent and Family Problems scale of the Questionnaire on Resources and Stress Friedrich Short Form, Hospital Anxiety and Depression Scale, Positive Affect scale of the Positive and Negative Affect Schedule, Reiss Scales for Children's Dual Diagnosis	• Maternal agency was positively correlated with pathways, positive affect and maternal education. • Maternal agency was negatively correlated with anxiety, depression, stress and challenging behaviour problems. • Maternal pathways was positively correlated with positive affect. • Maternal pathways was negatively correlated with anxiety, depression, stress and challenging behaviour problems. • Paternal agency was positively correlated with pathways, employment status and positive affect. • Paternal agency was negatively correlated with anxiety, depression. • Paternal pathways was positively correlated with positive affect. • Paternal pathways was negatively correlated with paternal age, child age, anxiety and depression. • Agency was a positive predictor of maternal and paternal positive affect, and a negative predictor of maternal depression and paternal anxiety and depression. • Pathways was a negative predictor of maternal depression. • Significant interaction – maternal depression was highest when both hope agency and hope pathways were low.

THS Trait Hope Scale

Study (year), Country [#]	Study Design, Data Collection Methodology	Statistical Analysis	Participant Characteristics & Sampling	Outcome Measures	Significant findings in relation to Hope
Ogston et al., (2011), USA [8]	Cross-sectional, online questionnaire answered on personal computer	Correlation, ANOVA, hierarchal linear regression	N=259 mothers of children with an ASD (N=130 autism, N=32 Asperger's syndrome N=37 PDD-NOS) or N=60 Down syndrome, recruited via notices on syndrome specific websites	SHS, The Penn State Worry Questionnaire, The Maternal Worry Scale for children with chronic illness, Autism Treatment Evaluation Checklist	• Hope was correlated positively with family income, maternal education, and maternal age. • Hope was correlated negatively with level of ASD impairment, parent rating of impairment, worry and future worry. • Hope varied by diagnosis (mothers of children with autism reported significantly lower hope than those of children with Down syndrome). • Dispositional worry was predicted by children who had a higher level of impairment and lower levels of hope. • Hope was predicted by diagnosis, level of ASD impairment and maternal education. (Hope was lower for those with less education and whose child was diagnosed with autism or had a more severe impairment.)
Truitt et al. (2012), USA [9]	Cross-sectional, contact letters detailing link to online survey	Correlation, regression, moderation	N=546 caregivers (N=406 biological mothers, N=22 biological fathers, N=18 other caregivers) of children with Down syndrome recruited through local and national support groups and Kennedy Krieger Institute patient list	THS, Trait 'Hope for the child scale', Parental Perceived Uncertainty Scale, Adaptation – 20 item scale	• Trait hope (for self) was highly positively correlated with trait hope for the child and negatively correlated with uncertainty. • There was no significant difference between the mean agency and pathways for trait hope (for self); however, mean agency was higher than mean pathways for hope for child scale. • Hope (for self) positively correlated with adaptation, predicted adaptation, but did not moderate the relationship between uncertainty and adaptation.

SHS State Hope Scale, *THS* Trait Hope Scale, *ASD* Autism spectrum disorder

Study (year), Country [#]	Study Design, Data Collection Methodology	Statistical Analysis	Participant Characteristics & Sampling	Outcome Measures	Significant findings in relation to Hope
Watson et al. (2013), Canada [10]	Mixed Methodology (cross-sectional and qualitative interviews), unclear how questionnaire data collected	T-test	N=85 parents (N=61 mothers, N=24 fathers) of children with ASD (N=68) or foetal alcohol spectrum disorder (FASD, N=27), recruited from a larger study via disability support organisations in Ontario, Canada, by respondent sampling	THS, Questionnaire on Resources and Stress Friedrich's Short Form	• There were no differences in hope between parents of children with ASD and FASD for agency, pathways or total hope.
Wheeler et al., (2008), USA [11]	Mixed methodology (cross-sectional and semi-structured interview), measures completed at home with researcher	Correlation, hierarchical multiple regression	N=101 mothers of children with full-mutation FXS recruited through existing studies at University of Carolina-Chapel Hill, the FXS participant research registry and posted notices on FXS Listserv and family support groups	THS, The Quality of Life Inventory, Parental Stress Index–short form, Structured Clinical Interview for DSM-IV-NP, Family Support Scale, Personal Assessment of Intimate Relationships Inventory: Emotional Intimacy Subscale, Fewell Religion Scale-adapted, WASI, Mullen Scales of Early Learning, Leiter International Performance Scales-Revised, Child Behavior Checklist, Childhood Autism Rating Scale	• Hope was positively correlated with quality of life. • Hope was negatively correlated with past depression and maternal education. • Hope predicted quality of life.

THS Trait Hope Scale, *FXS* Fragile X syndrome, *ASD* Autism spectrum disorder, *FASD* Foetal alcohol spectrum disorder

Table 5

Study appraisal of methodological quality

	Research question (max = 3)	Selection of participants (max = 15)	Assessment (max = 3)	Confounding variables (max = 3)	Statistical analysis (max = 3)	Quality of reporting (max = 6)	Percentage and quality category (good, fair, poor)*
Al-Yagon & Margalit (2009) [1]	3	7	1	2	2	4	58% (fair)
Bailey et al. (2008) [2]	2	9	3	1	3	1	58% (fair)
Baldry et al. (2005) [3]	3	9	3	1	2	4	67% (fair)
Einav et al. (2012) [4]	3	7	1	1	3	4	58% (fair)
Faso et al. (2013) [5]	3	10	3	1	3	3	70% (fair)
Horton & Wallander (2001) [6]	3	12	3	3	2	4	87% (good)
Lloyd & Hasting (2009) [7]	3	11	3	3	2	5	81% (good)
Ogston et al. (2011) [8]	3	10	3	3	3	3	76% (good)
Truitt et al. (2012) [9]	3	11	2	3	1	3	70% (fair)
Watson et al. (2013) [10]	2	3	3	1	1	2	36% (poor)
Wheeler et al. (2008) [11]	3	7	2	3	3	2	61% (fair)

**Good* (≥ 75%), *fair* (74-50%), *poor* (≤ 50%)

3.4 Synthesis of results

Hope in parents of children with a disability is an emerging area of research, with a limited literature base. All studies considered within final selection aimed to examine relationships between hope and other variables, while acknowledging the scarcity of current literature on this topic. For brevity, studies are referred to by their assigned number [#].

3.4.1 Demographics

Ten studies reported mean parental age, ranging from 34.9–47.81 years, but reporting of other demographic variables was mixed. Maternal age correlated positively with hope [8], whereas paternal age correlated negatively with pathways [7]. Six studies reported ethnicity, with a predominance of white ethnicity (range 77–94%) [2; 5; 6; 8; 9; 11], no relationship between ethnicity and hope was investigated.

Six studies reported financial earnings, with five studies showing a predominance of middle to high socio-economic status families [2; 5; 6; 8; 9; 11]. Agency was associated with paternal employment status [7] and hope was positively correlated with family income [8]. Two studies were conducted in Israel [1; 4] while the remainder were investigated in countries with a "western" culture (UK, USA, Canada and Australia).

Parental education was reported by eight studies, showing a bias towards parents educated to college or graduate degree level [1; 4; 5; 6; 7; 8; 9; 11]. Maternal education was positively correlated with agency [7] and hope [8]. In contrast, one study reported that maternal education was negatively correlated with hope [11]. This study [11] also reported that maternal education was negatively correlated with maternal IQ. Limited quality of reporting data on maternal education made interpretation of results difficult in this study.

Five studies reported marital status, with most participants being married (range 59–89%) [6; 7; 8; 9; 11]. Only one study investigated the relationship of marital status to hope, finding that maternal marital status was not associated with agency or pathways [7].

Most participants were mothers (N=1601). Four studies included fathers or other caregivers [3; 5; 7; 9]. Only two studies analysed parental data separately [5; 7]. There was no difference between the level of hope of mothers and fathers [5].

3.4.2 Sampling

Sample size varied from N=69-546. The representativeness of the samples to the population was rated as adequately or poorly addressed. Participants self-selected to take part in six studies [5; 6; 7; 8; 9; 11]. One study reported that participants were enrolled in a larger longitudinal study but did not provide details of how they were initially recruited [2].

Three studies used clinical samples. One study used support workers to recruit caregivers who were receiving a family support service and whose child was at risk of losing their home placement in New South Wales [3]. Two studies were conducted at the Shalva Centre in Jerusalem for "mentally and physically disabled children"; however, limited information was given as to how participants were recruited for these studies [1; 4].

Across studies, quality of reporting limited clarity of sampling methodology. Studies recruited caregivers through medical clinics [6], online sites [5; 8], schools [7], support groups [9], an intervention and respite centre [1; 4] and those who were in larger existing studies [2; 11]. Two studies acknowledged the use of a convenience sample [5; 6]. In all studies, participant selection and recruitment procedures increased the likelihood of selection bias.

Studies varied in the detail provided about the number of participants who were approached, who declined participation and who dropped out. In three studies this was due to recruitment methodology, using email lists or support groups, where numbers invited to take part may be incalculable [5; 8; 9]. Two studies provided information on those who dropped out reporting gender data, (24% mothers and 17% fathers dropped out [7]), and reason for non-participation (lack of time or energy [6]). From the quality of information provided by studies, it is hard to establish attrition bias.

3.4.3 Measurement of hope

Hope measurement was inconsistent across studies (see Table 6). Seven studies used the THS and three studies used the SHS [2; 3; 7]. Only one study provided rationale on choice of state versus trait measure [3]; because hope was measured at more than one time point, the SHS was used. Those studies that used the THS varied in use of a four-, six- or eight-point Likert scale. Two studies used a Hebrew adaptation of the THS [1; 4]. Two studies did not report descriptive statistics for hope [6; 7]. Three studies reported mean values for item scores rather than mean for total scale score [1; 4; 9]. Two studies analysed the components of agency and pathways separately [5; 7].

One study created a more specific parental hope measure: Hope for the Child [9]. It was positively correlated with the THS. No significant difference was identified between the mean agency and pathways for trait hope (for self); however, mean agency was higher than mean pathways for Hope for Child Scale [9]

3.4.4 Hope presentation in parents and caregivers

Poor quality of reporting descriptive statistics limited ability to draw comparisons between studies and to synthesise results across studies. A median value for each scale used by studies was therefore calculated (see Table 6). The median point for one item was calculated for each study's scale, which was multiplied by the number of items in that scale. For the eight studies which provided data, mean hope was

higher than the median value for that scale. This suggests that hope was present in parents and other caregivers.

Table 6

Measurement of hope

Study	Population	Description of measure used	Mean (SD) range	Median scale value
Al-Yagon & Margalit (2009) [1]	Mothers of children with developmental disorders	**THS** (Hebrew adaptation): six statements rated from 1 (none of the time) to 6 (all of the time).	Early Intervention group = 4.07 (0.68) * Respite Care group = 4.25 (0.99) *	3.5 (1–6)
Einav et al. (2012) [4]	Mothers of infants with development delay or disability	THS (Hebrew adaptation): six statements rated from 1 (never) to 6 (always).	4.11 (0.75) *	3.5 (1–6)
Faso et al. (2013) [5]	Parents of children with ASD	**THS**: twelve statements rated from 1 (definitely false) to 4 (definitely true). Agency and pathways separated in analysis.	Agency: Both parents = 25.5 (7.8) Mothers = 25.6 (4.0) Fathers = 25.1(5.3) Pathways: Both parents = 26.9 (3.9) Mothers = 26.9 (3.6) Fathers = 26.6 (4.9)	20 (4–32)
Horton & Wallander (2001) [6]	Mother of children with chronic physical conditions	**THS**: twelve statements rated from 1 (definitely false) to 4 (definitely true).	Descriptive statistics not reported. Results described as not normally distributed.	
Lloyd & Hasting (2009) [7]	Parents of children with ID	**THS**: twelve statements rated from 1 (definitely false) to 4 (definitely true).	Descriptive statistics not reported. Results 'likely to be reasonably normally distributed'. Agency and pathways separated in analysis.	
Truitt et al. (2012) [9]	Caregivers of children with Down syndrome	**THS** (for self) and Trait hope for the child both: twelve statements rated from 1 (definitely false) to 8 (definitely true).	Hope for self = 6.63 (0.875) 2.88–8.0† Hope for child = 6.64 (0.900) 3-8†	4.5 (1–8)
Wheeler et al. (2008) [10]	Mothers of children with FXS	**THS**: details not given but from descriptive statistics likely to be twelve statements from 1 (definitely false) to 8 (definitely true).	48.7 (9.23) 13–62	36 (8–64)
Bailey et al. (2008) [2]	Mothers of children with FXS	**SHS**: six statements rated from 1 (definitely false) to 8 (definitely true).	35.5 (8.1) 8–46	27 (8–48)
Baldry et al. (2005) [3]	Parents, grandparents and siblings of children with a disability whose placement is at risk	**SHS**: details not given but from data available likely to be with six statements rated from 1 (definitely false) to 8 (definitely true).	Pre-intervention = 30.9 (7.46) 13–46 Post-intervention = 34.1 (7.06) 17–48	27 (8–48)
Ogston et al. (2011) [8]	Mothers of children with an ASD or Down syndrome	**SHS**: six statements rated from 1 (definitely false) to 8 (definitely true).	Autism = 30.8 Asperger's syndrome = 33.0 PDD-NOS = 32.8 Down syndrome = 37.0	27(8–48)

*Item mean, *SHS* State Hope Scale, THS Trait Hope Scale, FXS Fragile X syndrome, ASD Autism Spectrum Disorder

3.4.5 Hope and child diagnosis

Two studies investigated children with FXS [2; 11], five included children with Down syndrome [1; 4; 7; 8; 9] and three included children with an ASD [5; 7; 8]. One study found that agency and pathways were not correlated with ASD or Down syndrome diagnosis [7]. However two studies found that maternal hope [8], maternal agency and paternal pathways [5] were negatively correlated with severity of autism symptoms and impairments. Both [7] and [8] had a quality rating of good. However [8] sampled a larger number of participants and separated ASD into different diagnoses, e.g. autism and Asperger syndrome.

Four studies tested differences between diagnosis groups [1; 2; 6; 8]. There was no significant difference in reported hope between mothers of children with Down syndrome versus intellectual disabilities with other aetiologies [1], or between mothers of children with permutation FXS versus full mutation FXS [2]. Mothers of children with autism had lower hope than mothers of children with Down syndrome [8]. In this study diagnosis independently predicted hope, explaining 8% of the variance. Parents of children with diabetes reported significantly more hope than parents of children with spina-bifida [6].

There was no difference between level of hope reported by mothers in early intervention (mean child age = 23.48 months) versus respite care (mean child age = 189.04 months, [1]). Data from the intervention study showed that hope significantly increased following intervention and continued to increase at six months post-intervention [4].

3.4.6 Hope and psychological variables

Hope was related to 16 positive and negative psychological variables measured in parents and caregivers. There was consistency across studies in the relationship between hope and adaptive variables, as well as between hope and less adaptive variables. Relationships were investigated through correlation analysis, regression

analysis and structural equation modelling. No power calculations were reported in any study. Quality of reporting and lack of effect sizes limited interpretation of the strength of results. Four studies did not report the relationship of hope with all psychological variables measured because it was not their primary research focus [1; 3; 9; 11]. Agency was significantly associated with more parental variables than pathways.

3.4.6.1 Hope and adaptive variables

Hope was consistently positively associated with other adaptive variables. Hope positively correlated with better quality of life and higher optimism in mothers of children with FXS [2; 11] and independently predicted their quality of life [11]. Hope also positively correlated with sense of coherence, use of coping strategies, greater family cohesion in mothers of children with developmental delay [4] and social support satisfaction in mothers of children with chronic health conditions [6]. Hope correlated positively with both family adaptability [4], and personal adaptability, with hope independently predicting the latter [9]. Hope positively correlated with both pre- and post-intervention levels of happiness [3]. Agency positively correlated with, and predicted, higher life satisfaction in mothers and fathers of children with ASD [5]. Hope predicted positive affect [1] and both agency and pathways positively correlated with positive affect in mothers and fathers of children with an ID [7]. The Trait Hope Scale correlated positively with two other measures of hope; the Vicarious Futurity Scale ("hope and despair a parent feels for the future of their child" [5]) and the Hope for the Child Scale [9].

3.4.6.2 Hope and less adaptive variables

Hope was consistently negatively associated with less adaptive variables. Hope negatively correlated with anxiety for mothers of children with FXS [2], as did agency and pathways in mothers and fathers of children with an ID [7]. The latter

study found that lower paternal agency predicted anxiety. Hope was also an independent predictor of dispositional worry, explaining 15% of the variance [8]. Hope negatively correlated with depression for mothers of children with FXS [2; 11]. Agency and pathways also negatively correlated with depression for mothers and fathers of children with ASD and children with an ID [5; 7]. Agency also predicted depressive symptoms in parents of children with ASD [5]. One study specifically found that maternal agency and pathways predicted depression [7]. However, pathways thinking only had an effect on maternal depression when the level of agency was low. Paternal agency also predicted depression [7]. Hope negatively correlated with anger for mothers of children with FXS [2].

Hope negatively correlated with stress in mothers of children with FXS [2], and in mothers of children with chronic physical health conditions [6]. Hope independently accounted for 4% of the variance in distress of mothers of children with chronic health conditions; more specifically, hope had a buffering role when stress was high [6]. The two studies analysed maternal and paternal data separately presented inconsistent findings on hope, parental gender and stress. One study found higher agency and pathways were associated with lower stress for mothers of children with ID (including Down syndrome and ASD) but not fathers [7]. Conversely, another study found that this association was true for fathers but not mothers of children with ASD [5]. This inconsistency could be reflective of the difference in methodology quality; one study [7] was rated as good and recruited a larger number of fathers in their sample compared with study [5] which was rated as fair. Child diagnosis varied between samples which may also have affected results.

3.4.7 Predictors of hope

Two studies focused specifically on hope [4; 8]. One study used structural equation modelling and found that sense of coherence and coping strategies predicted maternal hope [4]. Mothers with a high sense of coherence and greater coping strategies felt more hopeful. The second study used regression analysis and showed

that diagnosis, level of autism impairment and maternal education were independent predictors of hope [8]. Mothers' hope was lower for those with less education and who had children with autism or more severe impairment.

3.4.8 Child data

Eight studies reported mean child age. Two studies investigated "early intervention groups" with means of 1.96 years and 1.4 years [1; 4], six studies had a mean age within the primary school age ranging from 6–10.7 years [2; 6; 7; 8; 9; 11] and one study additionally investigated an older population with a mean of 15.75 years [1]. One study found that child age was not correlated to maternal hope [8] while another study found that child age negatively correlated with pathways in fathers [7]. Both these studies were rated as good quality.

Seven studies reported child gender [1; 4; 6; 7; 8; 9; 11], five of which had a higher proportion of males [4; 7; 8; 9; 11].Hope was not significantly related to child gender for mothers of children with ID [7].

Hope was significantly associated with better child outcomes. Agency and pathways correlated negatively with reported child behaviour problems in mothers but not in fathers of children with an ID [7]. Agency correlated negatively with reported autism symptom severity for mothers, but in fathers higher pathways correlated with lower symptom severity [5]. This, again, suggests that parents differ in their cognitive appraisals. However, interpretation is limited by the quality of studies. The severity of child physical disability was not related to hope [6].

4. Discussion

This review aimed to describe hope in parents of children with a disability and to synthesise findings in relation to psychological variables. Studies reported that hope was present in parents, and that it was significantly related to a range of

demographic and psychological variables in this population. Although seldom the focus of studies, hope presented as a potential resilience factor for parents. Studies demonstrated consistently that hope had adaptive relationships, with psychological variables; this is consistent with the presentation of hope in the general adult population (Shorey et al., 2007; Snyder et al., 1991). As with adults, hope was associated with better positive psychological variables such as coping (Snyder, 2000; 2002) and lower negative psychological variables such as depression (Chang, 2003; Chang & DeSimone, 2001). These findings are consistent with Snyder's model. Parents who were more hopeful, in that they appraised they could engage in goal-direction action and could identify a range of strategies to meet challenges, reported better outcomes for both themselves and their child.

Faso et al. (2013) reported no significant difference between the levels of hope in mothers and fathers. However, there were clear differences in findings across studies between maternal and paternal hope and their relationships demographic and psychological variables. Faso et al. (2013) found that hope in mothers and fathers had the same relationship with life satisfaction and depression but an opposite relationship with ASD symptom severity. In mothers increasing hope agency was associated with lower levels of ASD symptoms, compared to father were increasing hope pathways was associated with increasing level of ASD symptoms. Similarly, Lloyd and Hasting (2009) found hope, in mothers and fathers, had the same relationship with positive affect, anxiety and depression. However there was a range of variables which only correlated with mothers: level of education, stress, level of child challenging behaviour, and a range of variables which only correlated with fathers: employment status, parental age and child age.

Higher hope was also associated with better child outcomes, similar to findings with parents of children with externalising behaviour problems (Kashdan et al., 2002). This might highlight that, not only do parents with higher levels of hope think that they can engage in action and generate pathways but also are active in doing so;

this is consistent with previous research (Snyder, 2002). Most studies investigated caregivers of children with an intellectual or developmental disability. It may have been that the search terms used did not identify papers focused on children solely with a physical disability. More specific health or diagnosis search terms may be needed to generate a larger pool of published studies.

There was some evidence that caring for a child with an ASD was associated with and predicted lower levels of hope. Previous research has highlighted that children with ASD often develop early mental health difficulties (Brereton, Tonge, & Einfeld, 2006) which endure over time (Sabaratnam, Murthy, Wijeratne, Buckingham, & Payne, 2003). Children with ASD are also frequently rated as having more behaviour problems than children with an intellectual disability (Kasari & Sigman, 1997). The mechanism by which caring for a child with ASD affects parental hope, is unclear.

4.1 Limitations of synthesis

There is a paucity of evidence within the literature focusing specifically on hope in parents or caregivers of children with disabilities. This limited the number of studies eligible to meet the inclusion criteria for the review. The methodological quality of the papers identified affected the robustness of the synthesis, with only three studies rated as good quality. Due to the quality of reporting, clarity of recruitment methods and the self-selected nature of participants, the extent to which the evidence can be interpreted or generalised is limited. Recruitment methodologies may have meant that some studies were susceptible to self-selection bias, potentially recruiting parents experiencing more difficulties (Hamlyn-Wright et al., 2007). Poor quality of reporting meant that attrition bias was not calculable, with only two studies providing information on attrition rates. Therefore, it is not clear whether these results would be consistent across more diverse population.

Lack of comparison or control groups between children with different diagnoses in studies limits the extent to which findings can be considered generalisable across

populations with other disabilities. Also, any differences in the presentation of hope in parents who have a child with a disability compared to parents of typically developing children were not investigated. Participants were typically white, well-educated, married women from middle to high socio-economic backgrounds, supporting male primary school aged children, living in countries with a 'western' culture. Generalisability to populations outside these biases is therefore, inadvisable. Participant characteristics limit understanding of the presentation of hope in a less affluent or less educated population, who may also be less likely to take part in research. Use of different Likert scales and descriptive statistics reduced ability to compare findings across studies, and lack of effect sizes or power calculations limited understanding of the strength of evidence presented.

4.2 Limitations of the review

This review focused on the model of hope proposed by Snyder (Snyder, 2002; Snyder et al., 1991) to investigate one area within the literature on resilience factors specifically, hope. This focus generated an adequate number of papers to review, with only five papers using other models of hope. One limitation of the Snyder model is that it views hope as individualist and misses potential relational aspects of hope (Du & King, 2013). This view was highlighted by one study that choose to adapt the Trait Hope Scale to focus on the relationship between parent and child (Truitt et al., 2012). Faso et al., (2013) used the Vicarious Futurity Scale, designed to measure the vicarious hope and despair one individual has for another, in this case a parent for a child. However Faso et al., (2013) highlighted that this construct differentiated from trait hope, within Snyder's theory, by being dependant on a parent's feelings towards their child.

Sources of potential bias included language bias, country of origin (biased to "western" culture, other cultural settings may report differences in the manifestation of hope), use of specific databases, researcher bias (as final inclusion articles were selected by the author), and study quality bias (as most data was from

cross-sectional studies, with limited longitudinal data available). Due to resource constraints, studies not published in English were excluded. Most studies used an observational cross-section design which provides weaker evidence to ascertain causality and is more susceptible to selection bias, confounding, and potential reporting biases (Higgins & Green, 2008).

The tool used to assess methodological quality was adapted for this review from SIGN guidance (2008). SIGN was chosen as an established method to critically appraise evidence. However, bias may have been introduced into study appraisal, as the adapted tool had not been previously trialled. Although a total percentage was calculated to demonstrate relative strength, individual criteria had varying degrees of importance when assessing quality, e.g. selection of participants. Nevertheless, the tool provided a reflection of the quality of studies and was considered to adequately address areas relevant to the literature, e.g. use of validated measures.

The TSH and SHS are both positively scored measures, which may lead respondents to acquiescencent bias when completing items (Lloyd & Hastings, 2009). It may also explain why, in all studies, mean hope scored above the median value for that scale. However, the directionality and the degree of consistency from the evidence available, as well as the consistency of results with previous research, would suggest that the findings are a basis for future clinical practice and research.

4.3 Clinical implications

This review supports the identification of hope as a resilience factor in parents of children with a disability, given that it is associated with more adaptive psychological variables. In the context of previous literature, it is important to convey to professionals that hope is likely to be an adaptive resource in this population (Kearney & Griffin, 2001), consistent with the theoretical framework of hope that postulates there is no evidence for 'false hope' (Snyder, 2002).

Studies demonstrated that having a child with a disability does not inevitably mean lower hope, albeit that comparison groups with typically developing children were not used within studies. Consideration should be given towards factors that maintain and increase hope. This applies particularly to those that increase a parent's belief that a goal can be accomplished or the 'agency' component of hope, as this cognition showed the strongest associations with psychological variables. Studies identified that mothers and fathers report differences in relationships between hope and psychological variables. This could be considered when working with parents.

Hope could be used as an outcome measure to evaluate clinical intervention, similar to Baldry et al. (2005). Hope could be incorporated in assessments to identify 'at risk' parents, e.g. caring for children with autism (Ogston et al., 2011), to focus on psychological resources of parents when delivering preventative interventions, and to tailor intervention goals, consistent with government policy (Lloyd & Hasting, 2009; The Scottish Government 2012; 2013).

4.4 Research implications

This review highlighted inconsistency in the measurement of hope in the literature. One possible reason for this is the different Likert scoring reported in Snyder et al. (1991) and Snyder et al. (1996). Future research could address this by using the scales and scoring detailed in the latter paper, using an eight-point Likert scale. Although the THS was used by most studies, the associations of hope with parental age and child age may highlight a developmental perspective of the child-parental relationship to the expression of hope. Adaptation among parents to children's changing needs is considered reciprocal and dynamic (Hauser-Cram et al., 2001). Therefore, the SHS might more reliably measure the expression of hope relative to the changing needs and challenges of parenting children with a disability.

Truitt et al. (2012) adapted the THS to assess parental hope more reliably. Further validation of this measure would allow for increased understanding of the parent-child relationship, similar to other parental resilience cognitions, e.g. parental locus of control (Campis, Lyman & Prentice-Dunn, 1986).

Only two studies analysed agency and pathways separately, although it is established that the two components are distinct cognitions that can vary within an individual (Babyak et al., 1993; Snyder et al., 1991). The necessity of both components and their independence was supported by confirmatory factor analysis (Babyak, Snyder & Yoshinobu, 1993). Future research might investigate how psychological variables are related to both agency and pathways components as well as total hope. It may, therefore, aim to improve the quality of reporting hope data specifically including descriptive statistics for total and component hope scales and effect sizes.

There was an inconsistency in results between two studies, regarding the relationship between hope, stress and parental gender. Both studies (Faso et al, 2013; Lloyd & Hasting, 2009) were limited in their recruitment of fathers, reporting of recruitment methodology and the self-selecting nature of participants. Therefore, the relationship between these variables remains unclear and needs further investigation. Studies showed a clear difference between mothers and fathers and their relationships with hope. It would, therefore, be helpful to separate parents by gender in analysis. One study highlighted that mothers tended to be primary caregivers (Horton & Wallander, 2001), and another classified parents for analysis as primary or secondary carers for analysis (Baldry et al., 2005). Recognition of whether parents are primary or secondary caregivers could be a focus for future research to better understand the difference between study findings, rather than parental gender.

This review highlights gaps in the current research including data from parents of female children, comparison of parental hope between parents of typically developing children and children with a disability, and longitudinal data. Fathers or other caregivers were underrepresented in studies. Future research could include under-represented populations to aid generalisability of results and clarify the importance of care-giving roles, potentially using alternative methods of recruitment and participant selection. The cross-sectional design of studies limited understanding of causal links, such as whether hope is a cause or consequence of poorer psychological outcomes for parents. Prospective, long-term studies could examine causal associations more reliably.

Previous research into the relationship between hope and mental health variables, e.g. anxiety, led to the trial of hope-based interventions in the general adult population (Chearvers et al., 2006; Feldman & Dreher, 2012). Balfry et al. (2005) demonstrated that hope increased with intervention. Future research could include hope as an evaluation outcome or work towards hope-based interventions for this population.

5. Conclusions

Although parents of children with disabilities are more likely to experience distress, studies consistently showed the presence of hope in parents. The relationship between hope in parents of children with disabilities and psychological variables was consistent with findings in the general adult population. Results showed that hope was positively associated with adaptive variables, e.g. quality of life, and negatively associated with less adaptive variables, e.g. stress. Findings were limited by biases in the selection of participants, recruitment methods and poor quality of reporting. It is, therefore, suggested that there is a need to build on these initial findings, with further research required to understand the unique contributions of hope agency and pathways, as well as consistent measurement of hope, to develop

an evidence base to inform effective interventions and their evaluation in clinical practice.

Declaration of interest

This review was conducted as part of a portfolio thesis, for a Doctorate in Clinical Psychology, undertaken at the University of Edinburgh by the primary author. The author's place was funded jointly by NHS Education for Scotland and NHS Lothian. No other sponsorship, funding or support was received.

References

Al-Yagon, M. (2007). Socioemotional and Behavioral Adjustment Among School-Age Children with Learning Disabilities The Moderating Role of Maternal Personal Resources. *The Journal of Special Education*, *40*(4), 205-217.

Al-Yagon, M. (2009). Comorbid LD and ADHD in childhood: socioemotional and behavioural adjustment and parents' positive and negative affect. *European Journal of Special Needs Education, 24*(4), 371-391.

Al-Yagon, M., & Margalit, M. (2009). Positive and negative affect among mothers of children with intellectual disabilities. *British Journal of Developmental Disabilities, 55*(109,Pt2), 109-127.

Babyak, M. A., Snyder, C., & Yoshinobu, L. (1993). Psychometric properties of the Hope Scale: A confirmatory factor analysis. *Journal of Research in Personality, 27*(2), 154-169.

Bailey Jr, D. B., Sideris, J., Roberts, J., & Hatton, D. (2008). Child and genetic variables associated with maternal adaptation to fragile X syndrome: A multidimensional analysis. *American Journal of Medical Genetics, Part A, 146*(6), 720-729.

Baker-Ericzn, M. J., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research and Practice for Persons with Severe Disabilities, 30*(4), 194-204.

Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *Journal Information, 107*(6).

Baldry, E., Bratel, J., Dunsire, M., & Durrant, M. (2005). Keeping Children with a Disability Safely in their Families. *Practice, 17*(3), 143-156.

Barnum, D. D., Snyder, C., Rapoff, M. A., Mani, M. M., & Thompson, R. (1998). Hope and social support in psychological adjustment of children who have survived burn injuries and their matched controls. *Children's Health Care, 27*(1), 15-30.

Brereton, A. V., Tonge, B. J., & Einfeld, S. L. (2006). Psychopathology in children and adolescents with autism compared to young people with intellectual disability. *Journal of Autism and Developmental Disorders*, 36, 863–870.

Campis, L. K., Lyman, R. D., & Prentice-Dunn, S. (1986). The parental locus of control scale: Development and validation. *Journal of Clinical Child Psychology, 15*(3), 260-267.

Cicchetti, D. V. (2001). Methodological commentary the precision of reliability and validity estimates re-visited: distinguishing between clinical and statistical significance of sample size requirements. *Journal of Clinical and Experimental Neuropsychology*, *23*(5), 695-700.

Chang, E. C. (1998). Hope, problem-solving ability, and coping in a college student population: Some implications for theory and practice. *Journal of Clinical Psychology, 54*(7), 953-962.

Chang, E. C. (2003). A critical appraisal and extension of hope theory in middle-aged men and women: Is it important to distinguish agency and pathways components? *Journal of Social and Clinical Psychology, 22*(2), 121-143.

Chang, E. C., & DeSimone, S. L. (2001). The influence of hope on appraisals, coping, and dysphoria: A test of hope theory. *Journal of Social and Clinical Psychology, 20*(2), 117-129.

Cheavens, J. S., Feldman, D. B., Gum, A., Michael, S. T., & Snyder, C. (2006). Hope therapy in a community sample: A pilot investigation. *Social Indicators Research, 77*(1), 61-78.

Cousino, M. K., & Hazen, R. A. (2013). Parenting stress among caregivers of children with chronic illness: a systematic review. *Journal of pediatric psychology*, 39(8), 809-28.

CRD, Univeristy of York. (2009). *Systematic reviews: CRD's guidance for undertaking reviews in health care*. York: CRD, University of York.

Dagenais, L., Hall, N., Majnemer, A., Birnbaum, R., Dumas, F., Gosselin, J., ... & Shevell, M.

I. (2006). Communicating a diagnosis of cerebral palsy: caregiver satisfaction and stress. *Pediatric neurology*, *35*(6), 408-414.

Department for Children, Schools and Families. (2008). *Disabled Children: Numbers, characteristics and local service provision.* London: Author.

Du, H., & King, R. B. (2013). Placing hope in self and others: Exploring the relationships among self-construals, locus of hope, and adjustment. *Personality and Individual Differences, 54(3),* 332-337.

Einav, M., Levi, U., & Margalit, M. (2012). Mothers' coping and hope in early intervention. *European Journal of Special Needs Education, 27*(3), 265-279.

Farber, M. L., & Maharaj, R. (2005). Empowering high-risk families of children with disabilities. *Research on social work practice, 15*(6), 501-515.

Faso, D. J., Neal-Beevers, A. R., & Carlson, C. L. (2013). Vicarious futurity, hope, and well-being in parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 7*(2), 288-297.

Feldman, D. B., & Dreher, D. E. (2012). Can hope be changed in 90 minutes? Testing the efficacy of a single-session, goal-pursuit intervention for college students. *Journal of Happiness Studies, 13*(4), 745-759.

Hamlyn-Wright, S., Draghi-Lorenz, R., & Ellis, J. (2007). Locus of control fails to mediate between stress and anxiety and depression in parents of children with a developmental disorder. *Autism, 11*(6), 489-501.

Hassall, R., & Rose, J. (2005). Parental cognitions and adaptation to the demands of caring for a child with an intellectual disability: A review of the literature and implications for clinical interventions. *Behavioural and Cognitive Psychotherapy*, *33*(01), 71-88.

Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*(6), 405-418.

Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *Journal Information, 107*(2).

Hauser-Cram, P., Warfield, M. E., Shonkoff, J. P., Krauss, M. W., Sayer, A., Upshur, C. C., & Hodapp, R. M. (2001). Children with disabilities: A longitudinal study of child

development and parent well-being. *Monographs of the Society for Research in Child Development*, i-126.

Higgins, J. P., & Green, S. (2008). *Cochrane handbook for systematic reviews of interventions* (Vol. 5): Wiley Online Library.

Horsley, S., & Oliver, C. (2013). Positive impact and its relationship to well-being in parents of children with intellectual disability: a literature review. *International Journal of Developmental Disabilities*.

Horton, T. V., & Wallander, J. L. (2001). Hope and social support as resilience factors against psychological distress of mothers who care for children with chronic physical conditions. *Rehabilitation Psychology, 46*(4), 382-399.

Juvonen, J., & Leskinen, M. (1994). The function of onset and offset responsibility perceptions in fathers' and mothers' adjustment to their child's developmental disability. *Journal of Social Behavior & Personality, 9*(5), 349-368.

Kasari, C., & Sigman, M. (1997). Linking parental perceptions to interactions in young children with autism. *Journal of autism and developmental disorders*, *27*(1), 39-57.

Kashdan, T. B., Pelham, W. E., Lang, A. R., Hoza, B., Jacob, R. G., Jennings, J. R., . . . Gnagy, E. M. (2002). Hope and optimism as human strengths in parents of children with externalizing disorders: Stress is in the eye of the beholder. *Journal of Social and Clinical Psychology, 21*(4), 441-468.

Kausar, S., Jevne, R. F., & Sobsey, D. (2003). Hope in families of children with developmental disabilities. *Journal on Developmental Disabilities, 10*(1), 35-46.

Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: being a parent of a child with developmental disability. *Journal of advanced nursing, 34*(5), 582-592.

Kwon, P. (2000). Hope and dysphoria: The moderating role of defense mechanisms. *Journal of Personality*, *68*(2), 199-223.

Lloyd, T. J., & Hastings, R. (2009). Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities. *Journal of Intellectual Disability Research, 53*(12), 957-968.

McDonald, T. P., Poertner, J., & Pierpont, J. (1999). Predicting caregiver stress: An ecological perspective. *American Journal of Orthopsychiatry, 69*(1), 100-109.

Miller, J. F., & Powers, M. J. (1988). Development of an instrument to measure hope. *Nursing Research, 37*(1), 6-10.

Mednick, L., Cogen, F., Henderson, C., Rohrbeck, C. A., Kitessa, D., & Streisand, R. (2007). Hope more, worry less: Hope as a potential resilience factor in mothers of very young children with type 1 diabetes. Children's Healthcare, 36(4), 385-396.

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2010). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *International Journal of Surgery, 8*(5), 336-341.

Murphy, G. H., Beadle-Brown, J., Wing, L., Gould, J., Shah, A., & Holmes, N. (2005). Chronicity of challenging behaviours in people with severe intellectual disabilities and/or autism: A total population sample. *Journal of Autism and Developmental Disorders, 35*(4), 405-418.

Nachshen, J. S., & Minnes, P. (2005). Empowerment in parents of school-aged children with and without developmental disabilities. Journal of Intellectual Disability Research, 49(12), 889-904.

Oettingen, G., & Gollwitzer, P. M. (2002). Turning hope thoughts into goal-directed behavior. *Psychological Inquiry*, 304-307.

Ogston, P. L., Mackintosh, V. H., & Myers, B. J. (2011). Hope and worry in mothers of children with an autism spectrum disorder or Down syndrome. *Research in Autism Spectrum Disorders, 5*(4), 1378-1384.

Padencheri, S., & Russell, P. S. S. (2002). Challenging behaviours among children with intellectual disability: The hope busters? *Journal of Learning Disabilities, 6*(3), 253-261.

Peer, J. W., & Hillman, S. B. (2014). Stress and Resilience for Parents of Children With Intellectual and Developmental Disabilities: A Review of Key Factors and Recommendations for Practitioners. *Journal of Policy and Practice in Intellectual Disabilities, 11*(2), 92-98.

Peterson, C., & Seligman, M. E. (2004). Character strengths and virtues: A classification and handbook. *Washington, DC: American Psychological Association*.

Rand, K. L., & Cheavens, J. S. (2009). Hope theory. In C. R. Snyder & S. J. Lopez (Eds.), Oxford handbook of positive psychology (2nd ed., pp. 323–334). New York: Oxford University Press

Reder, E. A. K., & Serwint, J. R. (2009). Until the last breath: exploring the concept of hope for parents and health care professionals during a child's serious illness.

Archives of pediatrics & adolescent medicine, 163(7), 653-657.

Robitschek, C. (1996). At-Risk Youth and Hope: Incorporating a Ropes Course Into a Summer Jobs Program. *The Career Development Quarterly, 45*(2), 163-169.

Ruiz-Robledillo, N., De Andrés-García, S., Pérez-Blasco, J., González-Bono, E., & Moya-Albiol, L. (2014). Highly resilient coping entails better perceived health, high social support and low morning cortisol levels in parents of children with autism spectrum disorder. Research in developmental disabilities, 35(3), 686-695.

Sabaratnam, M., Murthy, V., Wijeratne, A., Buckingham, A., & Payne, S. (2003). Autistic-like behaviour profile and psychiatric morbidity in fragile X syndrome. *European Child and Adolescent Psychiatry*, 12, 172–177.

Scheier, M. F., & Carver, C. S. (1985). Optimism, coping, and health: assessment and implications of generalized outcome expectancies. *Health psychology, 4*(3), 219.

Seccombe, K. (2002). "Beating the odds" versus "changing the odds": Poverty, resilience, and family policy. *Journal of Marriage and Family, 64*(2), 384-394.

Shorey, H. S., Little, T. D., Snyder, C., Kluck, B., & Robitschek, C. (2007). Hope and personal growth initiative: A comparison of positive, future-oriented constructs. *Personality and Individual Differences, 43*(7), 1917-1926.

Scottish Intercollegiate Guidelines Network. (2008). *SIGN 50: a guideline developer's handbook*: Edinburgh: Author.

Snyder, C. R. (1995). Conceptualizing, measuring, and nurturing hope. *Journal of Counseling & Development, 73*(3), 355-360.

Snyder, C. R. (2000). The past and possible futures of hope. *Journal of Social and Clinical Psychology, 19*(1), 11-28.

Snyder, C. R. (2002). Hope theory: Rainbows in the mind. *Psychological Inquiry, 13*(4), 249-275.

Snyder, C. R., Harris, C., Anderson, J. R., Holleran, S. A., Irving, L. M., Sigmon, S. T., . . . Harney, P. (1991). The will and the ways: development and validation of an individual-differences measure of hope. *Journal of personality and social psychology, 60*(4), 570.

Snyder, C. R., Sympson, S. C., Ybasco, F. C., Borders, T. F., Babyak, M. A., & Higgins, R. L. (1996). Development and validation of the State Hope Scale. *Journal of personality and social psychology, 70*(2), 321.

Stotland, E. (1969). *The psychology of hope.* San Francisco: Jossey-Bass.

The Scottish Government. (2012). *Mental Health Strategy for Scotland: 2012-2015*. Edinburgh: Author.

The Scottish Government. (2013). *The keys to life – Improving Quality of Life for People with Learning Disabilities*. Edinburgh: Author.

Truitt, M., Biesecker, B., Capone, G., Bailey, T., & Erby, L. (2012). The role of hope in adaptation to uncertainty: The experience of caregivers of children with Down syndrome. *Patient Education and Counseling, 87*(2), 233-238. doi: http://dx.doi.org/10.1016/j.pec.2011.08.015

Watson, S., & Hayes, S. (2011). Does having hope help. *Resiliencies and challenges of families raising a child with autism. NADD Bulletin, 14*, 3-6.

Watson, S., Hayes, S., Radford-Paz, E., & Coons, K. (2013). "I'm hoping, I'm hoping..." Thoughts about the future from families of children with autism or fetal alcohol spectrum disorder in Ontario. *Journal on Developmental Disabilities, 19*(3), 76-9

Wheeler, A. C., Skinner, D. G., & Bailey, D. B. (2008). Perceived quality of life in mothers of children with fragile X syndrome. *American Journal of Mental Retardation, 113*(3), 159-177.

Wong, M. G., & Heriot, S. A. (2007). Vicarious futurity in autism and childhood dementia. *Journal of Autism and Developmental Disorders, 37*(10), 1833-1841.

Wong, M. G., & Heriot, S. A. (2008). Parents of children with cystic fibrosis: how they hope, cope and despair. *Child: care, health and development, 34*(3), 344-354.

Chapter 2: Empirical Paper

This chapter contains a journal article investigating hope and locus of control in mothers of children with an intellectual disability and challenging behaviour. It is formatted for submission to the 'Journal of Intellectual Disability Research' following the Harvard reference style as detailed in author guidelines (Appendix E).

Aims and Hypotheses

The current study aimed to describe the levels of, and associations between, parental hope, parental locus of control, parental knowledge of behaviour principles and level of child challenging behaviours reported by parents of children with an intellectual disability, through online recruitment. The study sought to explore parental hope specifically in relation to the aforementioned constructs.

It was hypothesised that:

- There would be an association between lower levels of reported challenging behaviour in children, higher parental hope, a more internal parental locus of control and greater knowledge of behavioural principles.
- Parental hope would be predicted by lower levels of reported behavioural problems, higher internal locus of control and increased knowledge of behavioural principles.

Mothers of children with an intellectual disability: investigating hope and locus of control

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Acknowledgements: This research study was conducted as part of a portfolio thesis, for a Doctorate in Clinical Psychology, undertaken at the University of Edinburgh by the primary author. The author's place was funded jointly by NHS Education for Scotland and NHS Lothian. No other sponsorship, funding or support was received.

Conflict of Interest Statement: No conflicts of interest have been declared.

Abstract

Background

Resilience factors are increasingly researched in the literature regarding parents of children with an intellectual disability (ID). Hope and parental locus of control are two such resilience factors. Hope is the perceived ability to achieve goals through two cognitive components, agency and pathways. Parental locus of control is a parent's perceived influence and control in the parent-child relationship. Knowledge of behavioural principles regarding challenging behaviour has been shown to affect the emotional reactions of school staff. It is unclear what level of knowledge of these principles exists in parents in the community and how knowledge affects resilience in parents or child behaviour. The purpose of this study was to explore relationships between two resilience factors, hope and locus of control, and their links with behavioural knowledge and challenging behaviour.

Method

An online cross-sectional survey was conducted with thirty-two mothers of children with an ID, using self-report measures: State Hope for the Child Scale (based on the State Hope Scale), Parental Locus of Control Scale (child control and parental control subscales), Behavior Problems Inventory for Individuals with Intellectual Disabilities – Short Form, and the Knowledge of Behavioural Principles Questionnaire (KBPQ), which was developed for this study.

Results

The majority of mothers were married/cohabiting (71.9%), living in areas of higher socio-economic status (70.3%), and caring for a child with a moderate or severe ID (78.2%). There was a higher incidence of children with autism spectrum disorder in this sample than population estimates for children with ID. Mothers reported feeling hopeful, although they experienced a range of challenging behaviours (mean 14.6 behaviours per child). Due to poor psychometric properties of the KBPQ,

data on mother's knowledge of behavioural principles was not included in the analysis; however, some areas of strength and weakness in knowledge were evident. Correlational analysis showed that higher levels of resilience factors were associated with lower levels of self-injurious and aggressive/destructive behaviour. Stereotyped behaviour was not associated with resilience factors. In contrast to previous research, higher hope was associated with a more external locus of control for the child control subscale.

Conclusions

Results replicated previous findings that maternal hope and locus of control are resilience factors and may be resources that could be bolstered to promote adaptation to stressors. This study added to the literature on how maternal hope and locus of control inter-relate in this population. Generalisability of results was limited by sample size, population characteristics and by scales used. However, findings suggest that it would be beneficial to consider resilience factors when planning and evaluating interventions. Implications for future research are discussed.

Keywords: intellectual disabilities, hope, locus of control, mother, behaviour

Introduction

Children with an intellectual disability (ID) have an increased risk of developing behavioural problems compared with typically developing children (e.g. Baker *et al.* 2002, Tonge & Einfeld, 2000). Such challenging behaviours have been defined as: "Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion" (RCP/BPS/RCSLT, 2007). Challenging behaviours include self-injury and aggression (Einfeld & Tonge, 1996; Pilling *et al.* 2007).

Families of children with an ID and challenging behaviour are significantly more likely to access services than those without challenging behaviour (Floyd & Gallagher, 1997), with approximately two-thirds of referrals to specialist child ID services identified with diagnosis of 'conduct disorders' (Emerson & Hatton, 2007). Moreover, mothers of children with an ID experience significantly more stress than mothers of typically developing children, with this increased stress associated with the emotional and behavioural problems displayed by their child (Baker *et al.* 2002, Baker *et al*. 2003; Peters -Scheffer *et al.* 2012).

However, parental stress and problem behaviours are thought to exist in a bi-directional relationship, where one exacerbates the other (Baker *et al.* 2003; Hastings *et al.* 2006; Lecavalier *et al.* 2006). Level of challenging behaviour is the most consistent predictor of parental wellbeing and stress (Abbeduto *et al.* 2004; Lloyd & Hastings, 2009a; Lecavalier *et al*. 2006) and was more important than adaptive behaviour or level of ID in predicting parental stress (Hastings *et al.* 2005). These findings highlight a need for services to identify means by which such behaviours could be moderated, in order to increase child and parental well-being. The links between family stressors, such as child challenging behaviour, resources

and coping have been summarised in family stress models within the ID literature. One such model frequently used is the Double ABCX model.

Double ABCX model of Family Stress and Coping

The ABCX family crisis model was proposed by Hill (1949, 1958). The stressful event (A), e.g. child behaviour, is met with the available family's resources (B) viewed through how the family define the event (C) that produces the crisis (X). This model was deemed to be limited by its focus on pre-crisis variables and Lazarus and Folkman (1984) postulated that stress is dependent on the cognitive appraisals arising from the interaction of the individual with the environment. A stressor occurs, therefore, when the subjective appraisal of the situation is judged as threatening or beyond current resources.

The ABCX model was extended by McCubbin and Patterson (1983), applying the theory developed by Lazarus and Folkman to families during stressful situations. Their Double ABCX model highlights the post-crisis effects of stressors, resources and interpretation of the stressful events over time. This model also included additional life stressors and strains (aA), psychological and social resources (bB), changes in the family's perception of the stressor (cC) and a range of outcomes for family adaptation (xX). These multivariate components capture more comprehensively the complexities of families caring for a child with a disability, thus the Double ABCX model is frequently used within the ID literature (e.g. Thompson *et al*. 2013).

The Double ABCX model postulates that families will access support services when the stressor, such as challenging behaviour, exceeds existing parental resources (Orr *et al.* 1991). According to the Double ABCX model, parents' cognitive appraisals directly influence parental stress as well as mediate the interaction between child behaviour and stress (Mash & Johnston, 1990). More recently, research has focused

on the role of cognitive appraisals associated with resilience as part of the wider trend of positive psychology (Hastings & Taunt, 2002). Two such resilience components identified from this research are hope and locus of control (LOC).

Hope

Hope has been identified as a resilience factor in both mothers and fathers of children with an ID (Lloyd & Hastings, 2009b), and is associated with better maternal psychological outcomes (e.g. Bailey *et al*. 2008, Einav *et al*. 2012). Hope, as defined by Snyder (2002; Snyder *et al.* 1991), is the perceived ability to achieve goals through two cognitive components: '*agency*', the resolve to motivate oneself to pursue goals and '*pathways*' the ability to formulate routes to accomplish goals. The agency component appraises the belief that one can initiate and maintain actions to achieve goals, and the pathways component appraises the ability to generate plans to meet goals.

Increased challenging behaviours have been associated with lower agency and lower pathways in mothers but not fathers (Lloyd & Hasting, 2009b). Parents of children displaying multiple challenging behaviours had significantly lower levels of hope than those displaying a single behaviour or no behaviours (Padencheri & Russell, 2002). Further understanding of the existing level of parental hope, as a potential parental resource in the Double ABCX model, could help tailor interventions to support parents.

Parental Locus of Control

LOC refers to cognitively appraising the degree to which individuals believe they can control the events that affect them (Lefcourt, 1979). Parental LOC is an adaptation of this concept focusing on a parent's perceived efficacy and power in the parent-child relationship (Campis *et al*. 1986). An *internal* parental LOC relates a parent's

belief that they can influence their child's behaviour and development, with their own parenting skills. This is in comparison to individuals with *external* parental LOC, who attribute their child's difficulties to other causes, resulting in them being less likely to change their own behaviour (Rotter, 1966).

Research has found that parental LOC style significantly influenced parental stress (Hassall *et al.* 2005; Lanfranchi & Vianello, 2012) and child behaviour (Freed & Tompson, 2011), making it a potential family resource within the Double ABCX model. Higher levels of challenging behaviour were significantly correlated with mothers who felt ineffective in their parenting role, felt unable to control their child's behaviour and who had an overall external LOC (Lloyd & Hastings, 2009a). The 'child (in) control' subscale, of the Parental Locus of Control Scale (Campis *et al*. 1986), in particular, has been consistently shown as a significant predictor of parental stress (Lanfranchi & Vianello, 2012; Lloyd & Hastings, 2009a). The relationship between hope and LOC in parents of children with an ID has not been studied. However, higher levels of hope in university students were associated with lower levels of external LOC (Brackney & Westman, 1992), suggesting the same association may be present in other adults.

This current literature highlights a gap in the understanding and presentation of hope and LOC style in parents of children with an ID, as family resources (bB) within the Double ABCX model. This understanding could help tailor future interventions targeting these variables, to provide better support for families coping with crisis or bolster resources to improve family adaptation to crisis.

Parenting Knowledge

General knowledge of child development has been associated with more positive child outcomes in the general population (Dichtelmiller *et al.* 1992). Increasing parental knowledge was found to moderate the relationship between confidence

and positive parenting behaviours (Morawska *et al.* 2009). This may highlight its influence on how families define and give meaning to a stressor (cC) within the Double ABCX model. Studies evaluating parental training interventions measure change in parental knowledge as an outcome (Chadwick *et al.* 2001; Matthews & Hudson, 2001; McConachie & Diggle, 2007).

For parents of children with an ID, providing more specific knowledge of behavioural principles is a key factor for interventions focused on challenging behaviour (Hastings, 1997). Given that limited knowledge of behavioural principles has been found to predict a depression/anger reaction to challenging behaviour in staff working in specialist ID education (Hastings & Brown, 2002), similar relationships might exist for parents of children with an ID. Most literature on knowledge focuses on staff in educational settings. Therefore, the level of knowledge in parents of children with an ID is unclear, particularly for knowledge of behavioural approaches that specialist services would typically advise. There are no previous studies demonstrating how parental resources such as hope or LOC interact with knowledge of behavioural principles.

Parents Online

The NHS has a growing presence online, providing information on a wide range of health topics (e.g. NHS Choices), and more specific mental health supports (e.g. 'www.handsonscotland.co.uk') for parents. The majority of parents report accessing websites both for information and social support (Plantin & Daneback, 2009). Some parents of children with an ID already use the internet to gain information and receive services (Blackburn & Read, 2005). Understanding the psychological characteristics of parents who use online media may help future studies aiming to target this population, such as providing online interventions.

Current Study

The current study aimed to describe the levels of, and associations between, parental hope, parental locus of control, parental knowledge of behaviour principles and level of child challenging behaviours reported by parents of children with an intellectual disability, through online recruitment. The study sought to explore parental hope specifically in relation to the aforementioned constructs. This study was originally part of a wider study evaluating the provision of an online psycho-educational intervention on challenging behaviour to parents of children with an ID.

It was hypothesised that:

- There would be an association between lower levels of reported challenging behaviour in children and higher parental hope, a more internal parental locus of control and greater knowledge of behavioural principles.
- Parental hope would be predicted by lower levels of reported behavioural problems, higher internal locus of control and increased knowledge of behavioural principles.

Ethical Approval

This project was reviewed and approved by The University of Edinburgh School of Health in Social Science ethics committee (Appendix F). The potential for distress caused by some of the questionnaires was highlighted in information provided prior to participation, as was participants' right to withdraw from the project at any stage.

Sample Calculation

A power-based sample size calculation for a medium effect size (Brackney & Westman, 1992), $p<.05$, $\beta=.8$ for three predictors in a multiple regression suggested

a minimum of 76 participants (Soper, 2014); however, the study aimed to recruit as many participants as possible.

Methods

Participants

Participants were self-selected. They confirmed that they supported a child or young person under the age of 18 who had a significant difficulty with intellectual functioning and daily living skills. Thirty-two mothers took part in this self-report, cross-sectional online survey. Mothers' mean age was 41.41 years (SD = 7.72, range = 27–56 years). Children's mean age was 11.17 years (SD = 3.77, range 4–18 years), with a gender ration of 22 males to 10 females. A total of 17 children had a diagnosis of an ASD (53.1%), 12.5% had a diagnosis of Down syndrome and 15.6% had a diagnosis of a specific genetic syndrome.

Measures

Participants provided demographic information regarding their child (age, gender, level of ID, educational setting, additional diagnoses, e.g. ASD), themselves (relationship to child, age, marital status and postcode) and other relevant variables (e.g. total number of children at home).

State Hope for the Child Scale (SHCS)

The State Hope Scale (Snyder *et al*. 1996) is an "in the moment" measure of a person's hope, assessing components of agency and pathways, and was developed from the Trait Hope Scale (Snyder *et al.* 1991). Both the State Hope Scale and the Trait Hope Scale have been used with parents of children with ID (e.g. Horton & Wallander, 2001; Lloyd & Hasting, 2009b). A state hope measure was chosen, as

this study was initially part of a wider evaluation of a psycho-educational intervention providing information on behavioural principles aimed at parents of children with an ID.

Truitt *et al.* (2012) investigated trait hope in caregivers of children with Down syndrome. They modified the Trait Hope Scale to investigate more specifically parental hope, conceptualised as the "Hope for the Child Scale". Specific modifications involved the additional wording of "my child" or "as a parent" to all items. In their study, the trait "hope for the child" scale had good internal consistency (α=.865) and was highly correlated with the trait hope for self (r=.654, p<.001).

As the current study also focused on the parental-child relationship, the State Hope Scale was adapted to measure "hope for the child". Changes were made following Truitt *et al.* (2012), to measure parental hope specifically as the 'State Hope for the Child Scale' (SHCS, Appendix G, used with permission). Consistent with the State Hope Scale, the SHCS was comprised of six items, coded as an eight-point Likert scale based on how respondents feel 'right now'. Higher scores reflect higher levels of hope. Three items represented hope agency and three items represented hope pathways. An example agency item was 'Right now, I see myself as being pretty successful **as a parent**' and an example pathway was 'I can think of many ways to reach my current goals **for my child**.'

Parental Locus of Control Scale (Campis et al. 1986): Child Control and Parental Control

The Parental Locus of Control Scale (PLOCS) is a self-report questionnaire measuring LOC associated with parenting. It is comprised of five subscales: parental efficacy, parental responsibility, child control, fate/chance and parental control. It demonstrated good construct and discriminant validity (Campis *et al.* 1986). In its

revised form, the PLOCS has demonstrated good internal consistency, α=.82 (Hassell *et al.* 2005).

The subscales of child control and parental control were strongly correlated with scores on the Parenting Stress Index, with other subscales having smaller or non-significant associations (Hassell *et al.* 2005; Lloyd & Hastings, 2009a). Together with level of behavioural problems, these two subscales predicted maternal stress (Lloyd & Hastings, 2009a). Recognising the known bi-directional relationship between stress and challenging behaviour, these two subscales were chosen to address this study's aims and to reduce participant burden. Parents were asked to agree or disagree with twelve items, where a higher score indicated more external LOC. Half of the items were reverse-scored (used with permission).

The Behavior Problems Inventory for Individuals with Intellectual Disabilities – Short Form (BPI-S; Rojahn et al. 2012a)

The Behavior Problems Inventory for Individuals with Intellectual Disabilities, Short Form (BPI-S, Rojahn *et al*. 2012a) is a 30-item measure of behaviour problems developed as a more user-friendly version of the BPI-01 (Rojahn *et al.* 2001). It records the frequency and severity of a range of behaviours across three subscales: self-injurious behaviour, aggressive/destructive behaviour and stereotyped behaviour. Frequency is scored on a five-point Likert scale, and severity is scored on a four-point scale. The BPI-S highly correlates with the BPI-01 (Rojahn *et al.* 2012a), and has been used in previous studies with children with developmental disabilities (Griffith *et al.* 2010). Rojahn *et al.* (2012b) demonstrated that the BPI-S has good construct validity and internal consistency (values ranging from α=.70–.89 across subscales, used with permission).

Knowledge of Behavioural Principles Questionnaire (KBPQ)

Existing measures to determine the extent of knowledge of behavioural principles relevant to working with challenging behaviour often use scenario-based questions, e.g. Problem Situation Questionnaire (McKillop, 1994) or Staff Knowledge of Behavioral Methods with Inpatient Youths (Lawrence & Hansen, 1985). However, these do not focus on the specific knowledge regarding challenging behaviour or children with ID. Hence there was a need to develop a questionnaire to measure knowledge to meet the aims of this study.

Previous work within the Child and Adolescent Mental Health Service (CAMHS) Learning Disability Team in NHS Lothian had led to the development of information for parents regarding behavioural principles relevant to challenging behaviour. This was based on relevant guidance available (Ball *et al*. 2004; RCP/ BPS/ RCSLT, 2007). From this, five keys themes were identified: reinforcement, extinction, positive behaviour support, developmental stage of child, and biological/environmental impact on child. Items were developed from these themes to form the Knowledge of Behavioural Principles Questionnaire (KBPQ) and scored using true or false statements based on previous research evaluating behavioural interventions by assessing specific knowledge in parents of children with ASD (e.g. Solish & Perry, 2008). Items were piloted and refined with multi-disciplinary health professionals working in specialist child ID services, including a Speech and Language Therapist, Clinical Psychologists and Psychiatrists. The final set of items was agreed and was considered by clinicians to have good face validity and clinical utility.

The KBPQ consisted of 19 items. An example item for reinforcement was: 'Reinforcement is something that occurs after a behaviour which means that the behaviour is more likely to happen in the future'. Item order was randomised and half of the items were reverse-scored.

Procedure

Participants were recruited through online communities. Relevant organisations, charities and support groups (Appendix H), e.g. BILD, were contacted for permission to recruit through their site. A link to a secure online survey site (Bristol Online Survey, www.onlinesurveys.ac.uk) was displayed with a brief description of the research and call for participants. Parents were encouraged to take part by the provision of online information on behaviour management tailored to support children with an ID. Links were disseminated through online forums, e-mail, e-newsletters and social media channels (Twitter and Facebook). Upon following the link, participants were presented with further information (Appendix I) and were invited to consent to take part. Study procedure followed BPS internet guidelines (BPS, 2013). Participants confirmed they currently cared for a child with an ID and were over sixteen years old.

The online survey was accessible for five months from 2nd April 2014 to 30th August 2014. A total of 47 participants commenced the survey. It was the intention of the study to recruit both mothers and fathers; however, only one father took part. His results were omitted from analysis, as previous research had indicated that mothers and fathers differ with regard to the links between hope and challenging behaviour (Faso et al., 2013; Lloyd & Hastings, 2009a). There were insufficient numbers of fathers to determine whether any differences were present in this sample. One mother reported that her child was aged 22 years. As this project focused on children aged 18 years or under, this data was excluded from results. Fifteen participants were excluded on the basis of non-completion of any measures (attrition rate 28.89%), yielding a total of 30 participants with complete data and two with partially complete data who were included in the final data analysis.

Analysis Strategy

Data were analysed using IBM® SPSS® Statistics Version 19. Normality of distribution was estimated with the Shapiro-Wilk test (Razali *et al.* 2011). Correlational analysis was used to test for significant associations between variables. An exploratory multiple regression analysis was planned, with hope as the dependant variable and independent variables of LOC, problem behaviour and knowledge of behavioural principles.

Results

Demographic characteristics are summarised in Table 1. Most mothers were married or living with their partner (71.9%) and had one (41.9%) or two children (38.7%) living at home.

Postcode data was used to classify the socio-economic status of where participants lived using the Scottish Index of Multiple Deprivation (http://simd.scotland.gov.uk/publication-2012/, The Scottish Government, 2012), the English Indices of Deprivation 2010 (http://opendatacommunities.org, Department for Communities and Local Government, 2011) or the Welsh Index of Multiple Deprivation (http://wimd.wales.gov.uk, Welsh Government, 2014), depending on their postcodes. The first decile represents the most deprived 10% of areas and the tenth decile the least deprived 10%, providing a measure of socio-economic status. Only four participants failed to provide their full postcode, which is required to calculate deprivation decile, hence it was not possible to determine socio-economic status for these participants.

Table 1 Mother and child demographic characteristics

Variable N=31	**Grouping**	**%**
Maternal age (years)	20–29	3.1
	30–39	46.9
	40–49	31.2
	50+	18.8
Marital status	Married/cohabiting	71.9
	Single parent	12.5
	Divorced	9.4
	Prefer not to say	6.3
Total children at home	1	41.9
	2	38.7
	3	16.1
	More than 3	3.2
Socio-economic status from deprivation decile (N=27)*	1	14.8
	2	7.4
	3	0
	4	7.4
	5	22.2
	6	7.4
	7	3.7
	8	14.8
	9	14.8
	10	7.4
Reported level of Intellectual Disability	Mild	6.3
	Moderate	43.8
	Severe	34.4
	Profound	6.3
	Don't know	9.4
Educational setting for child	Mainstream without support	6.3
	Mainstream with support	15.6
	Specialist Education	75.0
	Split placement	3.1

*1= most deprived 10%, 10= least deprived 10%

Mothers were more likely to have higher than average socio-economic status, with 70.3% ranked within the 5thdecile or above. The majority of children had a

moderate (43.8 %) or severe ID (34.4 %) and were supported in specialist education (75%).

The means, standard deviations and ranges of key variables within the study are presented in Table 2 (below).

Table 2 Descriptive statistics for study variables

	Mean	SD	Actual range	Potential range	N
State Hope for the Child	30.9	8.5	17-48	6-48	31
Hope Agency	15.3	4.7	7-24	3-24	31
Hope Pathways	15.5	4.4	8-24	3-24	31
Locus of Control					
Child Control of Parents' Life	8.6	1.5	6-12	6-12	32
Parental Control of Child's Behaviour	8.0	1.6	6-12	6-12	32
Self-injurious Behaviour					
Frequency	5.9	3.7	0-17	0-32	31
Severity	4.1	2.5	0-10	0-24	31
Aggressive/Destructive Behaviour					
Frequency	10.7	8.0	0-28	0-40	31
Severity	8.1	5.4	0-17	0-30	31
Stereotyped Behaviour (Frequency)	17.1	11.0	0-38	0-48	31
Knowledge of Behavioural Principles Questionnaire	12.9	1.8	10-17	0-18	30

Hope

There is no established clinical 'cut-off' score to indicate the presence of hope in an individual using the State Hope Scale. However, to aid interpretation Bailey *et al.* (2008) reasoned that a score of 24 or more would suggest an average rating of at least 'somewhat true' for items, indicating hope was present. Mean total hope was above this score at 30.9, with 81.25% of the sample scoring 24 or more. In the current study, reliability for the SHCS was good, as defined by George and Mallery

(2003: p.231), total hope α=.900, agency α=.863 and pathways α=.810. These reliability values are similar to those for the State Hope Scale (Snyder, 2002).

Locus of Control

On this scale, lower scores are associated with greater feelings of being in control. In the current study, data for the parental control subscale were positively skewed, indicating a tendency towards lower LOC score. Subscales had reliability of α=.487 for Child Control and α=.599 for parent control.

Level of Challenging Behaviour

The mean number of behaviours noted by mothers was 14.6 (range 3–25). All mothers reported experiencing some aggressive/destructive behaviour with their child, (mean frequency of 1.18). On average these behaviours occurred on a monthly or weekly basis. Behaviours noted by 20 mothers or more included: hitting others, pushing others, grabbing and pulling others, destroying things, repetitive hand movements, 'yelling and screaming' and 'pacing, jumping, bouncing, running'. Stereotyped behaviour had the highest mean frequency (1.38); only two parents reported their child did not engaged in any stereotyped behaviour. Mean severity rating for aggressive/destructive behaviour (0.82) was higher than for self-injurious behaviour (0.39). Reliability in the current study varied between subscales: self-injurious behaviour α=.623, aggressive/destructive behaviour α=. 914 and stereotyped behaviour α=.852.

Knowledge of Behavioural Principles

Reliability across all items within the KBPQ was low (α=.128). This suggests that it may not have been measuring a single construct. Therefore, an exploratory factor analysis was conducted to clarify whether specific items loaded to factors, most

probably matching the key themes utilised during questionnaire construction. It is acknowledged that the small sample size may be insufficient for this (Field, 2005), but it was felt that it might identify data within the KBPQ which could be used to support further analysis relating to the study aims. However, results indicated no clear underlying structure, with a high number of factors unrelated to the themes identified from the literature (eight linear components with Eigen values ranging from 3.1–1.04). It appears probable that the limited sample size was a contributory factor in this finding.

Although it was not possible to utilise the KBPQ in formal analysis, an overview of data suggested that some specific areas of strengths and deficits (even within themes) were present in participants. On the theme of *reinforcement*, most participants recognised that it occurs after behaviour has taken place (90% correct) and understood the concept of positive reinforcement (93.3%). However, few mothers recognised the futility of ignoring a child with an ID (23.3%) and the understanding of negative reinforcement was mixed (46.6%). Knowledge of the *extinction* theme was also mixed. Some mothers identified that an extinction burst meant that behaviour became more challenging (60%), but few understood why it occurred (26.6%).

Most mothers (more than 90%) identified that behaviour is often a form of communication for children with ID, and answered correctly questions on the theme of *positive behaviour support*, e.g. modelling appropriate behaviour and the utility of visual timetable. On the theme of *biological/environmental impact on child*, many mothers understood the association of illness and behaviour (63.3%) and the potential effect of a child's environment (76.6%). Some mothers struggled with knowledge on the theme of *developmental stage of the child*, such as the appropriateness of strategies such as "time-out" for this population (50%) and the unhelpfulness of spending a lot of time verbally explaining why they should stop behaviour (66.7%).

Autism Spectrum Disorder

Although not an original aim of the study, it was noted that respondents fell into two generally equal groups of participants with children with ASD (N= 17) and those without (N=15). As ASD has been found to affect both level of challenging behaviour and parental hope in some studies (Faso *et al*. 2013; Kasari & Sigman, 1997; Ogston *et al*. 2011; Totsika *et al*. 2011), an unplanned analysis was undertaken between these groups. A series of between-group t-tests were conducted to explore differences between respondents with children with and without ASD on study variables and demographic data. There was a significant difference only with educational placement, $t(30)= 2.59$, $p<.05$.

Correlational Analysis

Results of a Shapiro-Wilk test indicated non-normal distribution of data for socio-economic status (skewness=-.243, kurtosis= -1.114), level of ID (skewness= .847, kurtosis .557) and parent control subscale (skewness =.645, kurtosis =0.308). Remaining data was normally distributed.

Pearson's and Spearman's Rho correlations were used as applicable to explore associations between demographic data and outcome measures (see Table 3). As this was an exploratory study with low participant numbers, it was decided not to adjust for multiple test procedures, although it is acknowledged that this will increase the risk of a Type I error (Bender & Lange, 2001). Child's level of ID, gender of child and socio-economic status did not emerge as correlating significantly with any variable. Child age correlated with maternal age ($r=.483$, $p<.05$). Educational placement varied with level of child ID, as might be expected ($r_s=.483$, $p<.01$).

Hope

There were strong significant positive correlations between the hope subscales and the overall SHCS (see Table 3). Hope agency and pathways did not correlated with the same variables, reducing the representativeness of total SHCS as a summary score. Hope agency negatively correlated with frequency of self-injurious behaviour ($r= -.357$, $p<.05$). Hope pathways ($r=.502$, $p<.01$) and SHCS ($r=.443$, $p<.01$) associated with the child control LOC subscale. This indicated that with increasing hope participants tended to have a more external LOC.

Locus of Control

The LOC subscales correlated positively with each other, and a number of further significant correlations emerged between LOC and other variables, mainly those relating to challenging behaviours. Both subscales correlated negatively with self-injurious and aggressive/destructive behaviour, where decreasing levels of challenging behaviour were associated with a more internal LOC.

Child control negatively correlated with frequency and severity of self-injurious behaviour ($r=-.480$, $p<.01$; $r=-.484$, $p<.01$, respectively), as well as frequency and severity of aggressive/destructive behaviour and severity ($r=-.554$, $p<.01$; $r=-.536$, $p<.01$, respectively). Parental control negatively correlated with frequency of self-injurious behaviour and aggressive/destructive behaviour ($r_s=-.460$, $p<.01$; $r_s=-.679$, $p<.01$, respectively) and severity of aggressive/destructive behaviour ($r_s=-.642$, $p<.01$). Parental control also correlated with marital status ($r_s=.463$, $p<.01$), with married/cohabiting participants tending to have lower LOC scores, indicating a more internal LOC than single or divorced mothers.

Level of Challenging Behaviour

Most PBI-S subscales were significantly associated with each other. Stereotyped behaviour was associated with the severity of self-injurious behaviour and aggressive/destructive behaviour ($r=-.369$, $p<.05$; $r=-.363$, $p<.05$, respectively) but not with the frequency for either behaviour. Frequency of aggressive/destructive behaviour was negatively associated with child age and maternal age ($r=-.391$, $p<.05$; $r=-.417$, $p<.01$, respectively). Stereotyped behaviour was not associated with either hope or locus of control.

Table 3 Correlations between study variables

	1	2 [S]	3 [S]	4	5 [S]	6	7	8	9	10 [S]	11	12	13	14
1. Child age[S]	-													
2. Education[S]	.269	-												
3. Level of Child ID[S]	.145	.483**	-											
4. Maternal age	.483**	.332	.083	-										
5. Marital Status [S]	-.029	-.184	.139	-.230	-									
6. Hope Agency	.072	-.002	.108	-.239	.043	-								
7. Hope Pathways	-.072	-.180	-.076	-.275	.097	.767**	-							
8. State Hope for the Child Scale	.003	-.112	.004	-.273	.045	.944**	.935**	-						
9. Child Control	.227	.062	-.189	.142	.231	.336	.502**	.443**	-					
10. Parent Control [S]	.222	.100	.141	.318	.463**	.279	.223	.259	.531**	-				
11. Self-injurious (freq.)	-.111	.197	.318	-.099	-.115	-.357*	-.307	-.354	-.480**	-.460**	-			
12. Self-injurious (sev.)	-.104	.150	.354	-.058	.140	-.259	-.301	-.297	-.484**	-.213	.832**	-		
13. Aggressive/Destructive (freq.)	-.391*	-.098	-.034	-.417*	-.278	-.091	-.189	-.147	-.554**	-.679**	.476**	.496**	-	
14. Aggressive/Destructive (sev.)	-.151	.143	.008	-.239	-.210	-.028	-.150	-.093	-.536**	-.642**	.436**	.476**	.820*	-
15. Stereotyped (freq.)	.154	.178	.099	.121	-.157	.150	-.060	.052	-.066	-.073	.250	.369*	.239	.363*

*p <.05, ** p<.01, [S] Spearman's Rho, freq. = frequency, sev. = severity, KBPQ data not included due to unreliability of scale

Regression Analysis

The analysis plan for the study intended that a regression analysis would be conducted in order to identify the contribution of locus of control and knowledge of behavioural principles to hope. However, as noted above, the psychometric properties of the KBPQ were poor, and it was therefore excluded from further analysis. Hence, it was not possible to address this aim. Furthermore, it was also found that hope agency and hope pathways correlated with different study variables, making the total SHCS score less reliable as a representative summary score in regression analysis.

Discussion

This study aimed to examine relationships between parental hope, parental LOC, parental knowledge of behaviour principles and child challenging behaviours through participants recruited on-line. However, consistent with previous research, the vast majority of participants were female (Blackburn & Read, 2005; Sarkadi & Bremberg, 2004). Given that differences have been found in the ways that hope in mothers and fathers is associated with other psychological variables (Faso *et al.* 2013; Lloyd & Hasting, 2009a), the decision was taken to exclude the single male participant and focus solely on mothers.

Although participants reported that their child displayed a range of challenging behaviours, participants also reported feeling hopeful, something that is consistent with previous research (Bailey *et al*. 2008). Mean scores on the SHCS within the current sample were at an equivalent level to those found in samples using the State Hope Scale for parents of children with ASD (Ogston *et al*. 2011) but lower than reported hope for parents of children with Down syndrome or fragile X syndrome (Bailey *et al*. 2008; Ogston *et al*. 2011). This may have been due to the high number of mothers of children with ASD in the sample (N=17) compared to

mother of children with Down syndrome (N=5). As hypothesised, there was a relationship between hope and challenging behaviour. Hope agency was negatively associated with the frequency of self-injurious behaviour, suggesting that greater parental motivation and belief of achieving a goal for their child, links with lower frequency of self-injurious behaviour. Hope pathways and SHCS were positively associated with the child control subscale, indicating a more external parental LOC. This finding differs from previous research with university students, were higher hope was negatively associated with a more external LOC (Brackney & Westman, 1992). However, this sample reported caring for a child displaying a high level of challenging behaviours; a very different sample to Brackney and Westman (1992). Parental LOC is associated with both parental stress and child behaviour (Freed & Tompson, 2011; Lloyd & Hastings, 2009a). Therefore, this sample may represent mothers who feel hopeful and can think of a range of strategies to parent their child, but due to the level of challenging behaviour they still feel that their child controls their life to some extent. Within the double ABCX model, this may mean that maternal resources are present (bB) but are not at a level where they feel they can employ strategies because of the build-up of stressors (aA).

Maternal LOC was positively skewed in this sample, which was statistically significant for the parental control subscale. This indicates a more internal LOC. As hypothesised, there was a negative relationship between participants' LOC and reported challenging behaviour, which is in keeping with previous research indicating a more internal parental LOC is associated with fewer challenging behaviours (Freed & Tompson, 2011; Lloyd & Hastings, 2009). This highlights maternal LOC as a key resource (bB) within the double ABCX model. Consistent with previous findings, married/cohabiting mothers tended to have a more internal LOC than single or divorced mothers (Freed & Tompson, 2011). However, as both PLOC subscales had reliability below an 'acceptable' level (George & Mallery, 2003), results should be interpreted with caution.

Although maternal knowledge was assessed, it was not possible to analyse the hypothesised relationship with challenging behaviour or conduct the planned regression analysis to address the second hypothesis. However, review of responses within this questionnaire suggested that participants had some specific areas of strength and weakness in knowledge relevant to managing behaviours. Increasing knowledge remains a key outcome in parental training (Matthews & Hudson, 2001), and yet knowledge's potential role in the double ABCX model remains unclear.

All participants reported their child displayed at least three behaviours they found challenging on a regular basis. Mean frequency and severity scores were higher than age-matched peers from the reference data for all three subscales (Rojahn *et al*. 2012a). This may indicate a sample with higher levels of challenging behaviour than the general population of children with an ID. Frequency of aggressive/destructive behaviour was negatively associated with both child and maternal age, consistent with previous research (Chadwick *et al*. 2000, McConnell *et al*. 2014). Stereotyped behaviours were not associated with any maternal cognition. Stereotyped behaviours have been defined as repetitive voluntary unusual or inappropriate acts (Rojahn *et al*. 2001). This subscale included behaviours such as rocking, repetitive body movements and bizarre body postures. These behaviours have been shown to stop without external adult intervention and are thought to be triggered by a child's internal processing (Sayers *et al*. 2011), therefore, it is possible that they are likely to be affected by parental cognition.

Overall, the characteristics of the sample in this study mirror the population referred to specialist CAMHS ID services in terms of reported levels of behaviour, gender and proportion of children with an ASD diagnosis (Gregory *et al.* 2013). Although no specific ASD sites or groups were targeted for recruitment, over half of the sample reported that their child had an ASD (53.1%). ASD and ID are independent risk factors for challenging behaviour (Totsika *et al*. 2011). However, the co-morbidity of ASD and ID often presents challenges to those supporting

individuals, as there may be deficits in skills and behavioural difficulties not seen with ASD or ID alone (Boucher *et al*. 2008, Holden & Gitlesen, 2006). Children with an ASD are frequently noted to have more behaviour problems than children with ID (Kasari & Sigman, 1997) and these problems persevere in a co-morbid population (Murphy *et al.*2005). This may increase the build-up of stressors (aA) within the double ABCX model. Also, both agency and pathways were negatively correlated with autism symptoms severity (Faso *et al*. 2013). It has been found that mothers of children with an ASD had significantly lower levels of hope than mothers of children with Down syndrome (Ogston *et al*. 2011). Parents were encouraged to participate in the study in return for the provision of behavioural management strategies. Due to the additional burdens detailed above, it may be that parents of children with ASD are more likely to engage in online research or supports. However this study found no significant difference in the reported level of hope or challenging behaviour between mothers who cared for a child with an ASD and those whose child did not have a diagnosis.

Socio-economic status was not significantly associated with any study variables. However, the data was skewed to a sample that lived in areas with a lower level of deprivation. Financial hardship has been shown to have a negative impact on resilience (McConnel *et al*. 2014); therefore, this would be an important consideration for future research.

Clinical Implications

The results of this study supported previous findings that hope and LOC are resilience factors for parents supporting a child with an ID, and are associated with a lower level of challenging behaviour. If this is considered within the Double ABCX model of family adaptation, it would suggest that interventions should aim to bolster resilience resources. For example, increasing hope in parents of children with an ID could change parents' perceptions of 'set-backs' to that of 'challenges'

thus helping them to respond in a more adaptive way (Lloyd & Hastings, 2009b). Similar to previous research (Lloyd & Hastings, 2009a), the Child Control subscale of the PLOC revealed the strongest associations with study variables (hope and behaviour). Thus, items on the Child Control subscale, such as 'I feel like what happens in my life is mostly determined by my child', could be used in clinical settings to help identify more vulnerable parents, tailor interventions to increase internal LOC or used as an outcome measure of change to evaluate interventions (Lloyd & Hastings, 2009a). Although the relationship between hope and LOC needs further investigation, preliminary results of this study showed that higher hope pathways was not associated with a more adaptive internal LOC. This suggests that participants could potentially think of a range of strategies to parent their child, but felt that their child controlled their life to some extent. This may highlight that some mothers may need more from clinical interventions than a range of strategies to support their child, highlighting the importance of the agency component of hope.

This sample found no association between stereotyped behaviour and study variables. Previously conduct problems, including physical assaults, have been found to have the highest associations with caregiver and teacher stress (Lecavalier *et al*. 2006). Therefore, it might be more clinically efficient to focus on self-injurious and aggressive/destructive behaviour as goals for change.

The population sampled had characteristics similar to a clinical population. Within this sample it is unknown whether mothers were receiving support from services. However, there may be clinical utility to provide preventative interventions aiming to bolster resilience factors and to identify what resources they are using to maintain family adaptation (xX) to ongoing stressors such as challenging behaviour. Parents supporting a child with ID and challenging behaviour are more likely to access services (Floyd & Gallagher, 1997) when the stressor, such as challenging behaviour, exceeds existing parental resources (Orr *et al.* 1991). Although not included in statistical analysis, the KBPQ did highlight areas of more limited

knowledge. This could help clinicians tailor such interventions, within the Double ABCX model, to ensure that parents have appropriate knowledge to help them understand those stressors (cC) that impact on families' abilities to adapt to stressors (xX). As this sample had a higher proportion of mothers supporting a child with ASD, it might be worth considering their additional difficulties in any preventative intervention.

Study Limitations

The study's cross-sectional correlational design limits the conclusions that can be drawn regarding causality between variables. In this study, the difficulties with the psychometric properties of the KBPQ were a significant issue. Longitudinal data, with control or group comparisons, would support clarification of these links. The KBPQ was an attempt to quantify the extent of knowledge that parents held about relevant principles. However, although this is only a relatively small sample, review of responses suggests that mothers may not hold consistent levels of knowledge across an entire theme, such as 'reinforcement'; instead, they may have knowledge about specific items within that theme. Hence, the extent to which it is possible to assign a single measure of knowledge may be questionable. Instead, a longitudinal design, looking at changes in knowledge, perhaps through an intervention programme, and the extent to which this influences change in hope and locus of control, might be a means of addressing this limitation in the future.

A critical limitation of this study is the low number of participants, and hence the power to detect effects that may have been present. With regard to the scales used themselves, the limited numbers of participants are likely to have affected evaluations of the psychometric properties of both the established scales (PLOC, BPI-S) and the KBPQ. Thus, preventing the use of a regression analysis that was intended to answer one of the specific aims of the study. Although attempts were made to support recruitment through the use of several internet sites, additional

social media and forum sites, recruitment still proved difficult. This may have been due to recruiting during the school summer term and summer holiday period, when parents may have been less available to participate, or perhaps it is more of a reflection of the difficulties in recruiting participants online who are supporting a child with difficulties (Heiervang & Goodman, 2011).

This study was part of a wider evaluation of the psycho-educational intervention which aimed to recruit a diverse range of parents from online communities by offering information on behaviour management strategies. This may have influenced the sample who chose to take participate, or discouraged others because of the time commitment. As the evaluation study was specifically targeting parents who use online sites in the community, traditional paper questionnaires were not used. This may have limited participation of parents who use technology less frequently and parents from lower socio-economic backgrounds (Plantin & Daneback, 2009). However it may also highlight likely participant characteristics for future online interventions.

The generalisability of these results is limited by a number of factors. Self-selection increases the potential bias of recruiting parents who experience more difficulties (Hamlyn-Wright *et al.* 2007). This was reflected in the similarity of this sample to a clinical population (Gregory *et al*. 2013) and that the level of challenging behaviour was higher than age-matched peers (Rojahn *et al*. 2012a). These results may, therefore, not be reflective of the general population of parents who support a child with an intellectual disability. In addition, the focus upon mothers within the analysis (due to only a single father participating) limits the findings application to mothers. Furthermore, there was an underrepresentation of participants from areas of lower socio-economic status, as well as a high proportion of male children. Although these characteristics are similar to other studies which have recruited parents online (Sanders *et al*. 2014), and those investigating hope (Ogston *et al*. 2011), it limits the generalisability of results and highlights areas for future research.

Fathers of children with a disability are not well represented in the literature (Phares *et al*. 2005) and have previously been described as 'hard to reach' (McConkey, 1994). However, some researchers have highlighted how practitioners can include fathers (Carpenter & Towers, 2008) and developed ways of actively targeting fathers of children with developmental disabilities (Huang *et al.* 2014).

It is an acknowledged difficulty in research focused on individuals with ID to collect a homogeneous sample due to the wide range of aetiologies and co-morbid difficulties (e.g. Hooper & Willis, 2013). This study did not specifically aim to recruit parents of children with an ASD. However, there was a higher proportion of children with ASD in the sample (53.1%) compared to population estimates of 28–39.2% using specific ASD assessment tools (Bryson *et al*. 2008; La Malfa *et al*. 2004). These results may, therefore, not be generalisable to populations with lower proportions of parents with children with ASD.

The scales selected to measure variables also have limitations, something that further highlights the need to interpret results with caution. The SHCS was an adaption of the State Hope Scale, with the intention to measure, more specifically, parental hope. Although it was found to have good reliability, and produced similar results to previous research using the State Hope Scale, use of this measure needs further validation. Similar to criticisms of the State Hope Scale, the SHCS items are positively framed which may lead to response bias and, therefore, higher levels of reported hope. Only two of the PLOC subscales were utilised in this study, and reliability was below the 'acceptable range'. The KBPQ was developed for this study to measure specific knowledge of key principles of child behaviour typically discussed with families referred to specialist child ID services. Current measures are often scenario-based and do not cover the range of principles assessed in this study, e.g. Knowledge of Behavioural Principles as Applied to Children (O'Dell *et al.* 1979). However, the low reliability of the scale, and the absence of a clear factor structure (albeit that numbers of participants were very low for such an analysis to be reliable)

indicated that it may be difficult to assign a single value to the extent of an individual's knowledge of this area.

Future Research

Some specific research areas emerge from this study. It was an exploratory study that sought to investigate the relationship between hope, LOC and knowledge of behavioural principles in parents of children with an ID. However, due to the methodological difficulties outlined above, it was not possible to draw conclusions, with confidence, in relation to its aims.

In addition, a study focusing on recruitment of fathers might be of significant interest. Mothers and fathers have differing experiences of raising a child with an ID (Hastings *et al*. 2005). Therefore, future research could investigate whether results within the area of hope, LOC and knowledge are replicated with a sample of fathers, and potentially, with other populations that support children, e.g. grandparents or school staff. This may provide a more systemic perspective of links between resilience factors and child challenging behaviour.

Whilst this study focused on mothers in the community, it did not investigate-whether mothers were currently in crisis or receiving support from specialist agencies. Future research could compare resilience factors and challenging behaviour in populations in the community with those receiving specialist services. This could identify targets for improving family coping strategies before stressors, such as challenging behaviour, exceed existing parental resources. Additionally, this study focused on resilience factors. Future research could include a measure of parental stress to investigate potential mediation relationships between resilience factors, stress and challenging behaviour, in parents in the community and in those receiving specialist services.

Finally, marital status was significantly related to maternal LOC. Previous research has shown that single parents use services more than two-parent families (Floyd & Gallagher, 1997). Further research investigating the difference in resilience factors such as hope and LOC between married/cohabiting and single parents would inform the development of tailored preventative and post-crisis interventions.

Conclusions

This study aimed to evaluate links between hope, LOC, challenging behaviour and knowledge of behavioural principles of a sample of parents recruited on-line. Although relatively high levels of challenging behaviours, from their children, were described by participants, the majority reported experiencing hope in relation to parenting their child. Similar to previous studies, results indicated that more positive cognitive appraisals were associated with participants whose children displayed lower levels of self-injurious and aggressive/destructive behaviour. Due to methodological difficulties, it was not possible to clarify the relationships between the extent of knowledge about behavioural principles that a parent holds and their cognitions; however, it is possible that further development of a questionnaire to assess knowledge, or the use of a longitudinal design may make it possible to address this question fully. Nonetheless, it is suggested that the concept of hope, as a crucial cognition, merits further investigation for this population.

References

Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome or fragile X syndrome. *Journal Information, 109*(3).

Bailey Jr, D. B., Sideris, J., Roberts, J., & Hatton, D. (2008). Child and genetic variables associated with maternal adaptation to fragile X syndrome: A

multidimensional analysis. *American Journal of Medical Genetics, Part A, 146*(6), 720–729.

Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *Journal Information, 107*(6).

Baker, B. L., McIntyre, L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research, 47*(4-5), 217–230.

Ball, T., Bush, A., & Emerson, E. (2004). Psychological interventions for severely challenging behaviours shown by people with learning disabilities. *Aims & Scope*, 38.

Bender, R. & Lange, S. (2001). Adjusting for multiple testing—when and how? *Journal of clinical epidemiology*, *54*(4), 343–349.

Blackburn, C. & Read, J. (2005). Using the Internet? The experiences of parents of disabled children. *Child: Care, Health and Development, 31*(5), 507–515.

Brackney, B. E. & Westman, A. S. (1992). Relationships among hope, psychosocial development, and locus of control. *Psychological reports, 70*(3), 864–866.

British Psychological Society (2013). *Ethics Guidelines for Internet-mediated Research. INF206/1.2013.* Leicester: Author. Available from: www.bps.org.uk/publications/policy-andguidelines/research-guidelines-policydocuments/research-guidelines-poli

Campis, L. K., Lyman, R. D., & Prentice-Dunn, S. (1986). The parental locus of control scale: Development and validation. *Journal of Clinical Child Psychology, 15*(3), 260–267.

Carpenter, B., & Towers, C. (2008). Recognising fathers: the needs of fathers of children with disabilities. *Support for learning*, *23*(3), 118–125.

Chadwick, O., Momcilovic, N., Rossiter, R., Stumbles, E., & Taylor, E. (2001). A randomized trial of brief individual versus group parent training for behaviour problems in children with severe learning disabilities.

Behavioural and Cognitive Psychotherapy, 29(02), 151–167.

Daneback, K. & Plantin, L. (2008). Research on parenthood and the Internet: Themes and trends.

Department for Communities and Local Government. (2011). *English Indices of Deprivation 2010*. [ONLINE] Available at: http://opendatacommunities.org/deprivation/map. [Last Accessed 27.07.14].

Dichtelmiller, M., Meisels, S. J., Plunkett, J. W., BOZYTNSKI, M. E. A., Claflin, C., & Mangelsdorf, S. C. (1992). The relationship of parental knowledge to the development of extremely low birth weight infants. *Journal of Early Intervention, 16*(3), 210–220.

Einav, M. Levi, U. & Margalit, M. (2012). Mothers' coping and hope in early intervention. European Journal of Special Needs Education, 27(3), 265–279.

Einfeld, S. & Tonge, B. (1996). Population prevalence of psychopathology in children and adolescents with intellectual disability: II epidemiological findings. *Journal of Intellectual Disability Research, 40*(2), 99–109.

Emerson, E. & Hatton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *The British Journal of Psychiatry, 191*(6), 493–499.

Faso, D. J., Neal-Beevers, A. R., & Carlson, C. L. (2013). Vicarious futurity, hope, and well-being in parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 7*(2), 288-297.

Field, A. (2005). Discovering statistics with SPSS.

Floyd, F. J. & Gallagher, E. M. (1997). Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family Relations*, 359–371.

George, D. & Mallery, M. (2003). Using SPSS for Windows step by step: a simple guide and reference. *Boston, MA: Allyn y Bacon.[Links]*.

Gregory, S., Arnold, T., Sharman, C., Fraser, E., Lack, N., Froggatt, H., & Liverton,

G. (2013). The development of a Child and Adolescent Mental Health Service specifically for children with disabilities: reflections on the first four years. *Good Autism Practice (GAP), 14*(1), 68–73.

Griffith, G. M., Hastings, R. P., Nash, S., & Hill, C. (2010). Using matched groups to explore child behavior problems and maternal well-being in children with Down syndrome and autism. *Journal of Autism and Developmental Disorders, 40*(5), 610–619.

Hamlyn-Wright, S., Draghi-Lorenz, R., & Ellis, J. (2007). Locus of control fails to mediate between stress and anxiety and depression in parents of children with a developmental disorder. *Autism, 11*(6), 489–501.

Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*(6), 405–418.

Hastings, R. P. & Brown, T. (2002). Behavioural knowledge, causal beliefs and self-efficacy as predictors of special educators' emotional reactions to challenging behaviours. *Journal of Intellectual Disability Research, 46*(2), 144–150.

Hastings, R. P. & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *Journal Information, 107*(2).

Hastings, R. P. (1997). Staff beliefs about the challenging behaviors of children and adults with mental retardation. *Clinical Psychology Review, 17*(7), 775–790.

Hastings, R. P., Daley, D., Burns, C., & Beck, A. (2006). Maternal distress and expressed emotion: Cross-sectional and longitudinal relationships with behavior problems of children with intellectual disabilities. *Journal Information, 111*(1).

Hastings, R. P., Kovshoff, H., Ward, N. J., Degli Espinosa, F., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of*

Autism and Developmental Disorders, 35(5), 635–644.

Heiervang, E. & Goodman, R. (2011). Advantages and limitations of web-based surveys: evidence from a child mental health survey. *Social psychiatry and psychiatric epidemiology*, *46*(1), 69–76.

Hill, R. (1949). *Families under stress: Adjustment to the crises of war separation and reunion*. New York, Harper & Brothers.

Hill, R. (1958). Generic features of families under stress. *Social Casework*, 49, 139–150.

Hooper, S. R. & Willis, W. G. (2013). *Learning disability subtyping: Neuropsychological foundations, conceptual models, and issues in clinical differentiation*. Springer Science & Business Media.

Horton, T. V. & Wallander, J. L. (2001). Hope and social support as resilience factors against psychological distress of mothers who care for children with chronic physical conditions. *Rehabilitation Psychology*, *46*(4), 382.

Huang, Y. P., Chang, M. Y., Chi, Y. L., & Lai, F. C. (2014). Health-related quality of life in fathers of children with or without developmental disability: the mediating effect of parental stress. *Quality of Life Research*, *23*(1), 175–183.

Lanfranchi, S. & Vianello, R. (2012). Stress, Locus of Control, and Family Cohesion and Adaptability in Parents of Children with Down, Williams, Fragile X, and Prader-Willi Syndromes. *American journal on intellectual and developmental disabilities, 117*(3), 207-224.

Lazarus, R. S. & Folkman, S. (1984). Stress. *Appraisal, and coping*, *725*.

Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research, 50*(3), 172–183.

Lefcourt, H. M., von Baeyer, C. L., Ware, E. E., & Cox, D. J. (1979). The multidimensional-multiattributional causality scale: The development of a goal specific locus of control scale. *Canadian Journal of Behavioural Science/Revue canadienne des sciences du comportement, 11*(4), 286.

Leonard, H., Slack-Smith, L., Phillips, T., Richardson, S., D'Orsogna, L., & Mulroy, S.

(2004). How can the Internet help parents of children with rare neurologic disorders? *Journal of Child Neurology, 19*(11), 902–907.

Lloyd, T. & Hastings, R. (2009a). Parental locus of control and psychological well-being in mothers of children with intellectual disability. *Journal of Intellectual and Developmental Disability, 34*(2), 104–115.

Lloyd, T. J. & Hastings, R. (2009b). Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities. *Journal of Intellectual Disability Research, 53*(12), 957–968.

Mash, E. J. & Johnston, C. (1990). Determinants of parenting stress: Illustrations from families of hyperactive children and families of physically abused children. *Journal of Clinical Child Psychology, 19*(4), 313–328.

Matson, J. L. & Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities, 30*(6), 1107–1114.

Matthews, J. M. & Hudson, A. M. (2001). Guidelines for evaluating parent training programs. *Family Relations*, *50*(1), 77–86.

McConachie, H. & Diggle, T. (2007). Parent implemented early intervention for young children with autism spectrum disorder: a systematic review. *Journal of evaluation in clinical practice*, *13*(1), 120–129.

McConkey, R. (1994). Early intervention: planning futures, shaping years. *Mental Handicap Research*, *7*(1), 4-1.

McConnell, D., Savage, A., & Breitkreuz, R. (2014). Resilience in families raising children with disabilities and behavior problems. *Research in developmental disabilities*, *35*(4), 833–848.

McCubbin, H. I. & Patterson, J. M. (1983). The family stress process: The double ABCX model of adjustment and adaptation. *Marriage & Family Review, 6*(1–2), 7–37.

McKillop, J. M. (1994). A brief instrument to assess knowledge of behavioral principles. *Journal of behavior therapy and experimental psychiatry*, *25*(3), 251–253.

McLennan, D., Barnes, H., Noble, M., Davies, J., Garratt, E., & Dibben, C. (2011). The English indices of deprivation 2010. *London: Department for Communities and Local Government*.

Morawska, A., Winter, L., & Sanders, M. (2009). Parenting knowledge and its role in the prediction of dysfunctional parenting and disruptive child behaviour. *Child: Care, Health and Development, 35*(2), 217–226.

Murphy, G. H., Beadle-Brown, J., Wing, L., Gould, J., Shah, A., & Holmes, N. (2005). Chronicity of challenging behaviours in people with severe intellectual disabilities and/or autism: A total population sample. *Journal of Autism and Developmental Disorders, 35*(4), 405–418.

O'Dell, S. L., Tarler-Benlolo, L., & Flynn, J. M. (1979). An instrument to measure knowledge of behavioral principles as applied to children. *Journal of Behavior Therapy and Experimental Psychiatry, 10*(1), 29–34.

Ogston, P. L., Mackintosh, V. H., & Myers, B. J. (2011). Hope and worry in mothers of children with an autism spectrum disorder or Down syndrome. *Research in Autism Spectrum Disorders, 5*(4), 1378–1384.

Orr, R. R., Cameron, S. J., & Day, D. M. (1991). Coping with stress in families with children who have mental retardation: an evaluation of the double ABCX model. *American Journal on Mental Retardation*.

Padencheri, S. & Russell, P. S. S. (2002). Challenging behaviours among children with intellectual disability: The hope busters? *Journal of Learning Disabilities, 6*(3), 253–261.

Peters-Scheffer, N., Didden, R., & Korzilius, H. (2012). Maternal stress predicted by characteristics of children with autism spectrum disorder and intellectual disability. *Research in Autism Spectrum Disorders, 6*(2), 696–706.

Phares, V., Fields, S., Kamboukos, D., & Lopez, E. (2005). Still looking for Poppa. *American Psychologist, 60*(7), 735–736.

Pilling, N., McGill, P., & Cooper, V. (2007). Characteristics and experiences of children and young people with severe intellectual disabilities and

challenging behaviour attending 52-week residential special schools. *Journal of Intellectual Disability Research, 51*(3), 184–196.

Plantin, L. & Daneback, K. (2009). Parenthood, information and support on the internet. A literature review of research on parents and professionals online. *BMC Family Practice, 10*(1), 34.

Razali, N. M. & Wah, Y. B. (2011). Power comparisons of shapiro-wilk, kolmogorov-smirnov, lilliefors and anderson-darling tests. *Journal of Statistical Modeling and Analytics, 2*(1), 21–33.

Rojahn, J., Matson, J. L., Lott, D., Esbensen, A. J., & Smalls, Y. (2001). The Behavior Problems Inventory: An instrument for the assessment of self-injury, stereotyped behavior, and aggression/destruction in individuals with developmental disabilities. *Journal of Autism and Developmental Disorders, 31*(6), 577–588.

Rojahn, J., Rowe, E., Sharber, A., Hastings, R., Matson, J., Didden, R., . . . Dumont, E. (2012a). The Behavior Problems Inventory-Short Form for individuals with intellectual disabilities: Part I: development and provisional clinical reference data. *Journal of Intellectual Disability Research, 56*(5), 527–545.

Rojahn, J., Rowe, E., Sharber, A., Hastings, R., Matson, J., Didden, R., . . . Dumont, E. (2012b). The Behavior Problems Inventory-Short Form for individuals with intellectual disabilities: Part II: reliability and validity. *Journal of Intellectual Disability Research, 56*(5), 546–565.

Rotter, J. B. (1966). Generalized expectancies for internal versus external control of reinforcement. *Psychological monographs: General and applied, 80*(1), 1.

Sanders, M. R., Dittman, C. K., Farruggia, S. P., & Keown, L. J. (2014). A Comparison of Online Versus Workbook Delivery of a Self-Help Positive Parenting Program. *The Journal of Primary Prevention, 35*(3), 125–133.

Sarkadi, A. & Bremberg, S. (2005). Socially unbiased parenting support on the Internet: a cross-sectional study of users of a large Swedish parenting website. *Child: Care, Health and Development, 31*(1), 43–52.

Sayers, N., Oliver, C., Ruddick, L., & Wallis, B. (2011). Stereotyped behaviour in children with autism and intellectual disability: An examination of the executive dysfunction hypothesis. *Journal of Intellectual Disability Research*, *55*(7), 699–709.

Snyder, C. R. (2002). Hope theory: Rainbows in the mind. *Psychological Inquiry, 13*(4), 249–275.

Snyder, C. R., Harris, C., Anderson, J. R., Holleran, S. A., Irving, L. M., Sigmon, S. T., . . . Harney, P. (1991). The will and the ways: development and validation of an individual-differences measure of hope. *Journal of personality and social psychology, 60*(4), 570.

Snyder, C. R., Sympson, S. C., Ybasco, F. C., Borders, T. F., Babyak, M. A., & Higgins, R. L. (1996). Development and validation of the State Hope Scale. *Journal of personality and social psychology, 70*(2), 321.

Solish, A. & Perry, A. (2008). Parents' involvement in their children's behavioral intervention programs: Parent and therapist perspectives. *Research in Autism Spectrum Disorders, 2*(4), 728–738.

Soper, D.S. (2014). *A-priori Sample Size Calculator for Multiple Regression* [Software]. Available at: http://www.danielsoper.com/statcalc

The Royal College of Psychiatrists, The British Psychological Society and The Royal College of Speech and Language Therapists (2007). Challenging behaviour: A unified approach (Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices). London: Author.

The Scottish Government (2012). *Scottish Index of Multiple Deprivation*. [ONLINE] Available at: http://simd.scotland.gov.uk/publication-2012/. [Last Accessed 10.07.15].

Thompson, S., Hiebert-Murphy, D., & Trute, B. (2013). Parental perceptions of family adjustment in childhood developmental disabilities. *Journal of Intellectual Disabilities*, *17*(1), 24–37.

Tonge, B. & Einfeld, S. (2000). The trajectory of psychiatric disorders in young

people with intellectual disabilities. *Australian and New Zealand Journal of Psychiatry, 34*(1), 80–84.

Truitt, M., Biesecker, B., Capone, G., Bailey, T., & Erby, L. (2012). The role of hope in adaptation to uncertainty: The experience of caregivers of children with Down syndrome. *Patient Education and Counseling, 87*(2), 233–238.

Welsh Assembly Government (2014). *Welsh Index of Multiple Deprivation*. . [ONLINE] Available at: http://wimd.wales.gov.uk/?lang=en.[Last Accessed 10.07.15].

Portfolio Thesis References

Abbeduto, L., Seltzer, M. M., Shattuck, et al., (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome or fragile X syndrome. *Journal Information, 109*(3).

Al-Yagon, M. (2007). Socioemotional and Behavioral Adjustment Among School-Age Children with Learning Disabilities The Moderating Role of Maternal Personal Resources. *The Journal of Special Education*, *40*(4), 205-217.

Al-Yagon, M. (2009). Comorbid LD and ADHD in childhood: socioemotional and behavioural adjustment and parents' positive and negative affect. *European Journal of Special Needs Education, 24*(4), 371-391.

Al-Yagon, M., & Margalit, M. (2009). Positive and negative affect among mothers of children with intellectual disabilities. *British Journal of Developmental Disabilities, 55*(109,Pt2), 109-127.

American Psychological Association (2010). *Publication manual of the American Psychological Association*. Washington, DC (EUA): Author.

Babyak, M. A., Snyder, C., & Yoshinobu, L. (1993). Psychometric properties of the Hope Scale: A confirmatory factor analysis. *Journal of Research in Personality, 27*(2), 154-169.

Bailey Jr, D. B., Sideris, J., Roberts, J., & Hatton, D. (2008). Child and genetic variables associated with maternal adaptation to fragile X syndrome: A multidimensional analysis. *American Journal of Medical Genetics, Part A, 146*(6), 720-729.

Bailey Jr, D. B., Sideris, J., Roberts, J., & Hatton, D. (2008). Child and genetic variables associated with maternal adaptation to fragile X syndrome: A multidimensional analysis. *American Journal of Medical Genetics, Part A, 146*(6), 720–729.

Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without

developmental delays. *Journal Information, 107*(6).

Baker, B. L., McIntyre, L., Blacher, J., et al., (2003). Pre-school children with and without developmental delay: behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research, 47*(4-5), 217–230.

Baker-Ericzn, M. J., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research and Practice for Persons with Severe Disabilities, 30*(4), 194-204.

Baldry, E., Bratel, J., Dunsire, M., & Durrant, M. (2005). Keeping Children with a Disability Safely in their Families. *Practice, 17*(3), 143-156.

Ball, T., Bush, A., & Emerson, E. (2004). Psychological interventions for severely challenging behaviours shown by people with learning disabilities. *Aims & Scope*, 38.

Barnum, D. D., Snyder, C., Rapoff, M. A., et al., (1998). Hope and social support in psychological adjustment of children who have survived burn injuries and their matched controls. *Children's Health Care, 27*(1), 15-30.

Bender, R. & Lange, S. (2001). Adjusting for multiple testing—when and how? *Journal of clinical epidemiology*, *54*(4), 343–349.

Blackburn, C. & Read, J. (2005). Using the Internet? The experiences of parents of disabled children. *Child: Care, Health and Development, 31*(5), 507–515.

Brackney, B. E. & Westman, A. S. (1992). Relationships among hope, psychosocial development, and locus of control. *Psychological reports, 70*(3), 864–866.

Brereton, A. V., Tonge, B. J., & Einfeld, S. L. (2006). Psychopathology in children and adolescents with autism compared to young people with intellectual disability. *Journal of Autism and Developmental Disorders*, 36, 863–870.

British Psychological Society (2013). *Ethics Guidelines for Internet-mediated Research. INF206/1.2013.* Leicester: Author.

British Psychological Society (2015). Style Guide for authors and editors. Leicester: Author.

Campis, L. K., Lyman, R. D., & Prentice-Dunn, S. (1986). The parental locus of control scale:

Development and validation. *Journal of Clinical Child Psychology, 15*(3), 260-267.

Carpenter, B., & Towers, C. (2008). Recognising fathers: the needs of fathers of children with disabilities. *Support for learning*, *23*(3), 118–125.

Chadwick, O., Momcilovic, N., Rossiter, R., et al., (2001). A randomized trial of brief individual versus group parent training for behaviour problems in children with severe learning disabilities. *Behavioural and Cognitive Psychotherapy, 29*(02), 151–167.

Chang, E. C. (1998). Hope, problem-solving ability, and coping in a college student population: Some implications for theory and practice. *Journal of Clinical Psychology, 54*(7), 953-962.

Chang, E. C. (2003). A critical appraisal and extension of hope theory in middle-aged men and women: Is it important to distinguish agency and pathways components? *Journal of Social and Clinical Psychology, 22*(2), 121-143.

Chang, E. C., & DeSimone, S. L. (2001). The influence of hope on appraisals, coping, and dysphoria: A test of hope theory. *Journal of Social and Clinical Psychology, 20*(2), 117-129.

Cheavens, J. S., Feldman, D. B., Gum, A., et al., (2006). Hope therapy in a community sample: A pilot investigation. *Social Indicators Research, 77*(1), 61-78.

Cicchetti, D. V. (2001). Methodological commentary the precision of reliability and validity estimates re-visited: distinguishing between clinical and statistical significance of sample size requirements. *Journal of Clinical and Experimental Neuropsychology*, *23*(5), 695-700.

Cousino, M. K., & Hazen, R. A. (2013). Parenting stress among caregivers of children with chronic illness: a systematic review. *Journal of pediatric psychology*, 39(8), 809-28.

CRD, Univeristy of York. (2009). *Systematic reviews: CRD's guidance for undertaking reviews in health care*. York: CRD, University of York.

Dagenais, L., Hall, N., Majnemer, A., et al., (2006). Communicating a diagnosis of cerebral

palsy: caregiver satisfaction and stress. *Pediatric neurology*, *35*(6), 408-414.

Daneback, K. & Plantin, L. (2008). Research on parenthood and the Internet: Themes and trends.

Department for Children, Schools and Families. (2008). *Disabled Children: Numbers, characteristics and local service provision.* London: Author.

Department for Communities and Local Government. (2011). *English Indices of Deprivation 2010*. [ONLINE] Available at: http://opendatacommunities.org/deprivation/map. [Last Accessed 27.07.14].

Dichtelmiller, M., Meisels, S. J., Plunkett, J. W., et al., (1992). The relationship of parental knowledge to the development of extremely low birth weight infants. *Journal of Early Intervention, 16*(3), 210–220.

Du, H., & King, R. B. (2013). Placing hope in self and others: Exploring the relationships among self-construals, locus of hope, and adjustment. *Personality and Individual Differences, 54(3),* 332-337.

Einav, M. Levi, U. & Margalit, M. (2012). Mothers' coping and hope in early intervention. European Journal of Special Needs Education, 27(3), 265–279.

Einfeld, S. & Tonge, B. (1996). Population prevalence of psychopathology in children and adolescents with intellectual disability: II epidemiological findings. *Journal of Intellectual Disability Research, 40*(2), 99–109.

Emerson, E. & Hatton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *The British Journal of Psychiatry, 191*(6), 493–499.

Farber, M. L., & Maharaj, R. (2005). Empowering high-risk families of children with disabilities. *Research on social work practice, 15*(6), 501-515.

Faso, D. J., Neal-Beevers, A. R., & Carlson, C. L. (2013). Vicarious futurity, hope, and well-being in parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 7*(2), 288-297.

Feldman, D. B., & Dreher, D. E. (2012). Can hope be changed in 90 minutes? Testing the

efficacy of a single-session, goal-pursuit intervention for college students. *Journal of Happiness Studies, 13*(4), 745-759.

Field, A. (2005). Discovering statistics with SPSS.

Floyd, F. J. & Gallagher, E. M. (1997). Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family Relations*, 359–371.

George, D. & Mallery, M. (2003). Using SPSS for Windows step by step: a simple guide and reference. *Boston, MA: Allyn y Bacon.[Links]*.

Gregory, S., Arnold, T., Sharman, C., et al., (2013). The development of a Child and Adolescent Mental Health Service specifically for children with disabilities: reflections on the first four years. *Good Autism Practice (GAP), 14*(1), 68–73.

Griffith, G. M., Hastings, R. P., Nash, S., & Hill, C. (2010). Using matched groups to explore child behavior problems and maternal well-being in children with Down syndrome and autism. *Journal of Autism and Developmental Disorders, 40*(5), 610–619.

Hamlyn-Wright, S., Draghi-Lorenz, R., & Ellis, J. (2007). Locus of control fails to mediate between stress and anxiety and depression in parents of children with a developmental disorder. *Autism, 11*(6), 489-501.

Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*(6), 405–418.

Hastings, R. P. & Brown, T. (2002). Behavioural knowledge, causal beliefs and self-efficacy as predictors of special educators' emotional reactions to challenging behaviours. *Journal of Intellectual Disability Research, 46*(2), 144–150.

Hastings, R. P. & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *Journal Information, 107*(2).

Hastings, R. P. (1997). Staff beliefs about the challenging behaviors of children and adults

with mental retardation. *Clinical Psychology Review, 17*(7), 775–790.

Hastings, R. P., Daley, D., Burns, C., & Beck, A. (2006). Maternal distress and expressed emotion: Cross-sectional and longitudinal relationships with behavior problems of children with intellectual disabilities. *Journal Information, 111*(1).

Hastings, R. P., Kovshoff, H., Ward, N. J., et al.,(2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders, 35*(5), 635–644.

Hauser-Cram, P., Warfield, M. E., Shonkoff, J. P., et al., (2001). Children with disabilities: A longitudinal study of child development and parent well-being. *Monographs of the Society for Research in Child Development*, i-126.

Heiervang, E. & Goodman, R. (2011). Advantages and limitations of web-based surveys: evidence from a child mental health survey. *Social psychiatry and psychiatric epidemiology*, *46*(1), 69–76.

Higgins, J. P., & Green, S. (2008). *Cochrane handbook for systematic reviews of interventions* (Vol. 5): Wiley Online Library.

Hill, R. (1949). *Families under stress: Adjustment to the crises of war separation and reunion*. New York, Harper & Brothers.

Hill, R. (1958). Generic features of families under stress. *Social Casework*, 49, 139–150.

Hooper, S. R. & Willis, W. G. (2013). *Learning disability subtyping: Neuropsychological foundations, conceptual models, and issues in clinical differentiation*. Springer Science & Business Media.

Horsley, S., & Oliver, C. (2013). Positive impact and its relationship to well-being in parents of children with intellectual disability: a literature review. *International Journal of Developmental Disabilities*.

Horton, T. V. & Wallander, J. L. (2001). Hope and social support as resilience factors against psychological distress of mothers who care for children with chronic physical conditions. *Rehabilitation Psychology*, *46*(4), 382.

Huang, Y. P., Chang, M. Y., Chi, Y. L., & Lai, F. C. (2014). Health-related quality of life in fathers of children with or without developmental disability: the mediating effect of parental stress. *Quality of Life Research*, *23*(1), 175–183.

Juvonen, J., & Leskinen, M. (1994). The function of onset and offset responsibility perceptions in fathers' and mothers' adjustment to their child's developmental disability. *Journal of Social Behavior & Personality, 9*(5), 349-368.

Kasari, C., & Sigman, M. (1997). Linking parental perceptions to interactions in young children with autism. *Journal of autism and developmental disorders*, *27*(1), 39-57.

Kashdan, T. B., Pelham, W. E., Lang, et al., (2002). Hope and optimism as human strengths in parents of children with externalizing disorders: Stress is in the eye of the beholder. *Journal of Social and Clinical Psychology, 21*(4), 441-468.

Kausar, S., Jevne, R. F., & Sobsey, D. (2003). Hope in families of children with developmental disabilities. *Journal on Developmental Disabilities, 10*(1), 35-46.

Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: being a parent of a child with developmental disability. *Journal of advanced nursing, 34*(5), 582-592.

Kwon, P. (2000). Hope and dysphoria: The moderating role of defense mechanisms. *Journal of Personality*, *68*(2), 199-223.

Lanfranchi, S. & Vianello, R. (2012). Stress, Locus of Control, and Family Cohesion and Adaptability in Parents of Children with Down, Williams, Fragile X, and Prader-Willi Syndromes. *American journal on intellectual and developmental disabilities, 117*(3), 207-224.

Lazarus, R. S. & Folkman, S. (1984). Stress. *Appraisal, and coping*, *725*.

Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research, 50*(3), 172–183.

Lefcourt, H. M., von Baeyer, C. L., Ware, E. E., & Cox, D. J. (1979). The multidimensional-multiattributional causality scale: The development of a goal specific locus of control scale. *Canadian Journal of Behavioural Science/Revue canadienne des*

sciences du comportement, 11(4), 286.

Leonard, H., Slack-Smith, L., Phillips, T., Richardson, S., D'Orsogna, L., & Mulroy, S. (2004). How can the Internet help parents of children with rare neurologic disorders? *Journal of Child Neurology, 19*(11), 902–907.

Lloyd, T. & Hastings, R. (2009). Parental locus of control and psychological well-being in mothers of children with intellectual disability. *Journal of Intellectual and Developmental Disability, 34*(2), 104–115.

Lloyd, T. J., & Hastings, R. (2009). Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities. *Journal of Intellectual Disability Research, 53*(12), 957-968.

Mash, E. J. & Johnston, C. (1990). Determinants of parenting stress: Illustrations from families of hyperactive children and families of physically abused children. *Journal of Clinical Child Psychology, 19*(4), 313–328.

Matson, J. L. & Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities, 30*(6), 1107–1114.

Matthews, J. M. & Hudson, A. M. (2001). Guidelines for evaluating parent training programs. *Family Relations*, *50*(1), 77–86.

McConachie, H. & Diggle, T. (2007). Parent implemented early intervention for young children with autism spectrum disorder: a systematic review. *Journal of evaluation in clinical practice*, *13*(1), 120–129.

McConkey, R. (1994). Early intervention: planning futures, shaping years. *Mental Handicap Research*, *7*(1), 4-1.

McConnell, D., Savage, A., & Breitkreuz, R. (2014). Resilience in families raising children with disabilities and behavior problems. *Research in developmental disabilities*, *35*(4), 833–848.

McCubbin, H. I. & Patterson, J. M. (1983). The family stress process: The double ABCX model of adjustment and adaptation. *Marriage & Family Review, 6*(1–2), 7–37.

McDonald, T. P., Poertner, J., & Pierpont, J. (1999). Predicting caregiver stress: An ecological perspective. *American Journal of Orthopsychiatry, 69*(1), 100-109.

McKillop, J. M. (1994). A brief instrument to assess knowledge of behavioral principles. *Journal of behavior therapy and experimental psychiatry*, *25*(3), 251–253.

McLennan, D., Barnes, H., Noble, M., et al., (2011). The English indices of deprivation 2010. *London: Department for Communities and Local Government*.

Mednick, L., Cogen, F., Henderson, C., et al., (2007). Hope more, worry less: Hope as a potential resilience factor in mothers of very young children with type 1 diabetes. Children's Healthcare, 36(4), 385-396.

Miller, J. F., & Powers, M. J. (1988). Development of an instrument to measure hope. *Nursing Research, 37*(1), 6-10.

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2010). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *International Journal of Surgery, 8*(5), 336-341.

Morawska, A., Winter, L., & Sanders, M. (2009). Parenting knowledge and its role in the prediction of dysfunctional parenting and disruptive child behaviour. *Child: Care, Health and Development, 35*(2), 217–226.

Murphy, G. H., Beadle-Brown, J., Wing, L., et al., (2005). Chronicity of challenging behaviours in people with severe intellectual disabilities and/or autism: A total population sample. *Journal of Autism and Developmental Disorders, 35*(4), 405-418.

Murphy, G. H., Beadle-Brown, J., Wing, L et al.,(2005). Chronicity of challenging behaviours in people with severe intellectual disabilities and/or autism: A total population sample. *Journal of Autism and Developmental Disorders, 35*(4), 405–418.

Nachshen, J. S., & Minnes, P. (2005). Empowerment in parents of school-aged children with and without developmental disabilities. Journal of Intellectual Disability Research, 49(12), 889-904.

O'Dell, S. L., Tarler-Benlolo, L., & Flynn, J. M. (1979). An instrument to measure knowledge of behavioral principles as applied to children. *Journal of Behavior Therapy and*

Experimental Psychiatry, 10(1), 29–34.

Oettingen, G., & Gollwitzer, P. M. (2002). Turning hope thoughts into goal-directed behavior. *Psychological Inquiry*, 304-307.

Ogston, P. L., Mackintosh, V. H., & Myers, B. J. (2011). Hope and worry in mothers of children with an autism spectrum disorder or Down syndrome. *Research in Autism Spectrum Disorders, 5*(4), 1378-1384.

Orr, R. R., Cameron, S. J., & Day, D. M. (1991). Coping with stress in families with children who have mental retardation: an evaluation of the double ABCX model. *American Journal on Mental Retardation*.

Padencheri, S., & Russell, P. S. S. (2002). Challenging behaviours among children with intellectual disability: The hope busters? *Journal of Learning Disabilities, 6*(3), 253-261.

Peer, J. W., & Hillman, S. B. (2014). Stress and Resilience for Parents of Children With Intellectual and Developmental Disabilities: A Review of Key Factors and Recommendations for Practitioners. *Journal of Policy and Practice in Intellectual Disabilities, 11*(2), 92-98.

Peterson, C., & Seligman, M. E. (2004). Character strengths and virtues: A classification and handbook. *Washington, DC: American Psychological Association*.

Peters-Scheffer, N., Didden, R., & Korzilius, H. (2012). Maternal stress predicted by characteristics of children with autism spectrum disorder and intellectual disability. *Research in Autism Spectrum Disorders, 6*(2), 696–706.

Phares, V., Fields, S., Kamboukos, D., & Lopez, E. (2005). Still looking for Poppa. *American Psychologist, 60*(7), 735–736.

Pilling, N., McGill, P., & Cooper, V. (2007). Characteristics and experiences of children and young people with severe intellectual disabilities and challenging behaviour attending 52-week residential special schools. *Journal of Intellectual Disability Research, 51*(3), 184–196.

Plantin, L. & Daneback, K. (2009). Parenthood, information and support on the internet. A

literature review of research on parents and professionals online. *BMC Family Practice, 10*(1), 34.

Rand, K. L., & Cheavens, J. S. (2009). Hope theory. In C. R. Snyder & S. J. Lopez (Eds.), Oxford handbook of positive psychology (2nd ed., pp. 323–334). New York: Oxford University Press

Razali, N. M. & Wah, Y. B. (2011). Power comparisons of shapiro-wilk, kolmogorov-smirnov, lilliefors and anderson-darling tests. *Journal of Statistical Modeling and Analytics, 2*(1), 21–33.

Reder, E. A. K., & Serwint, J. R. (2009). Until the last breath: exploring the concept of hope for parents and health care professionals during a child's serious illness. *Archives of pediatrics & adolescent medicine, 163*(7), 653-657.

Robitschek, C. (1996). At-Risk Youth and Hope: Incorporating a Ropes Course Into a Summer Jobs Program. *The Career Development Quarterly, 45*(2), 163-169.

Rojahn, J., Matson, J. L., Lott, D., Esbensen, A. J., & Smalls, Y. (2001). The Behavior Problems Inventory: An instrument for the assessment of self-injury, stereotyped behavior, and aggression/destruction in individuals with developmental disabilities. *Journal of Autism and Developmental Disorders, 31*(6), 577–588.

Rojahn, J., Rowe, E., Sharber, A., et al., (2012). The Behavior Problems Inventory-Short Form for individuals with intellectual disabilities: Part I: development and provisional clinical reference data. *Journal of Intellectual Disability Research, 56*(5), 527–545.

Rojahn, J., Rowe, E., Sharber, A., et al., (2012). The Behavior Problems Inventory-Short Form for individuals with intellectual disabilities: Part II: reliability and validity. *Journal of Intellectual Disability Research, 56*(5), 546–565.

Rotter, J. B. (1966). Generalized expectancies for internal versus external control of reinforcement. *Psychological monographs: General and applied, 80*(1), 1.

Ruiz-Robledillo, N., De Andrés-García, S., Pérez-Blasco, J., et al., (2014). Highly resilient coping entails better perceived health, high social support and low morning cortisol

levels in parents of children with autism spectrum disorder. Research in developmental disabilities, 35(3), 686-695.

Sabaratnam, M., Murthy, V., Wijeratne, A., Buckingham, A., & Payne, S. (2003). Autistic-like behaviour profile and psychiatric morbidity in fragile X syndrome. *European Child and Adolescent Psychiatry*, 12, 172–177.

Sanders, M. R., Dittman, C. K., Farruggia, S. P., & Keown, L. J. (2014). A Comparison of Online Versus Workbook Delivery of a Self-Help Positive Parenting Program. *The Journal of Primary Prevention, 35*(3), 125–133.

Sarkadi, A. & Bremberg, S. (2005). Socially unbiased parenting support on the Internet: a cross-sectional study of users of a large Swedish parenting website. *Child: Care, Health and Development, 31*(1), 43–52.

Sayers, N., Oliver, C., Ruddick, L., & Wallis, B. (2011). Stereotyped behaviour in children with autism and intellectual disability: An examination of the executive dysfunction hypothesis. *Journal of Intellectual Disability Research*, *55*(7), 699–709.

Scheier, M. F., & Carver, C. S. (1985). Optimism, coping, and health: assessment and implications of generalized outcome expectancies. *Health psychology, 4*(3), 219.

Scottish Intercollegiate Guidelines Network. (2008). *SIGN 50: a guideline developer's handbook*: Edinburgh: Author.

Seccombe, K. (2002). “Beating the odds” versus “changing the odds”: Poverty, resilience, and family policy. *Journal of Marriage and Family, 64*(2), 384-394.

Shorey, H. S., Little, T. D., Snyder, C., Kluck, B., & Robitschek, C. (2007). Hope and personal growth initiative: A comparison of positive, future-oriented constructs. *Personality and Individual Differences, 43*(7), 1917-1926.

Snyder, C. R. (1995). Conceptualizing, measuring, and nurturing hope. *Journal of Counseling & Development, 73*(3), 355-360.

Snyder, C. R. (2000). The past and possible futures of hope. *Journal of Social and Clinical Psychology, 19*(1), 11-28.

Snyder, C. R. (2002). Hope theory: Rainbows in the mind. *Psychological Inquiry, 13*(4), 249-275.

Snyder, C. R., Harris, C., Anderson, J. R., et al., (1991). The will and the ways: development and validation of an individual-differences measure of hope. *Journal of personality and social psychology, 60*(4), 570.

Snyder, C. R., Sympson, S. C., Ybasco, F. C., Borders, T. F., Babyak, M. A., & Higgins, R. L. (1996). Development and validation of the State Hope Scale. *Journal of personality and social psychology, 70*(2), 321.

Snyder, C. R., Sympson, S. C., Ybasco, F. C., et al., (1996). Development and validation of the State Hope Scale. *Journal of personality and social psychology, 70*(2), 321.

Solish, A. & Perry, A. (2008). Parents' involvement in their children's behavioral intervention programs: Parent and therapist perspectives. *Research in Autism Spectrum Disorders, 2*(4), 728–738.

Soper, D.S. (2014). *A-priori Sample Size Calculator for Multiple Regression* [Software]. Available at: http://www.danielsoper.com/statcalc

Stotland, E. (1969). *The psychology of hope.* San Francisco: Jossey-Bass.

The Royal College of Psychiatrists, The British Psychological Society and The Royal College of Speech and Language Therapists (2007). Challenging behaviour: A unified approach (Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices). London: Author.

The Scottish Government (2012). *Scottish Index of Multiple Deprivation*. [ONLINE] Available at: http://simd.scotland.gov.uk/publication-2012/. [Last Accessed 10.07.15].

The Scottish Government. (2012). *Mental Health Strategy for Scotland: 2012-2015*. Edinburgh: Author.

The Scottish Government. (2013). *The keys to life – Improving Quality of Life for People with Learning Disabilities*. Edinburgh: Author.

Thompson, S., Hiebert-Murphy, D., & Trute, B. (2013). Parental perceptions of family adjustment in childhood developmental disabilities. *Journal of Intellectual Disabilities*, *17*(1), 24–37.

Tillich, P. (1990). *Theology of peace*. Louisville: Westminster/John Knox Press.

Tonge, B. & Einfeld, S. (2000). The trajectory of psychiatric disorders in young people with intellectual disabilities. *Australian and New Zealand Journal of Psychiatry, 34*(1), 80–84.

Truitt, M., Biesecker, B., Capone, G., et al., (2012). The role of hope in adaptation to uncertainty: The experience of caregivers of children with Down syndrome. *Patient Education and Counseling, 87*(2), 233–238.

Watson, S., & Hayes, S. (2011). Does having hope help. *Resiliencies and challenges of families raising a child with autism. NADD Bulletin, 14*, 3-6.

Watson, S., Hayes, S., Radford-Paz, E., & Coons, K. (2013). "I'm hoping, I'm hoping..." Thoughts about the future from families of children with autism or fetal alcohol spectrum disorder in Ontario. *Journal on Developmental Disabilities, 19*(3), 76-9

Welsh Assembly Government (2014). *Welsh Index of Multiple Deprivation*. . [ONLINE] Available at: http://wimd.wales.gov.uk/?lang=en. [Last Accessed 10.07.15].

Wheeler, A. C., Skinner, D. G., & Bailey, D. B. (2008). Perceived quality of life in mothers of children with fragile X syndrome. *American Journal of Mental Retardation, 113*(3), 159-177.

Wong, M. G., & Heriot, S. A. (2007). Vicarious futurity in autism and childhood dementia. *Journal of Autism and Developmental Disorders, 37*(10), 1833-1841.

Wong, M. G., & Heriot, S. A. (2008). Parents of children with cystic fibrosis: how they hope, cope and despair. *Child: care, health and development, 34*(3), 344-354.

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The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

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Appendix B: Systematic Review Protocol (based on the University of York, Centre for Reviews and Dissemination's guidance for undertaking review in health care)

Objective: Systematically examine the available literature on a specific parental cognition: Hope. Focus on studies that investigated the relationship between hope, within Snyder's model of hope agency and pathways, and the psychological outcomes of parents who have a child with a disability, with the aim of informing future research and clinical interventions.

Possible publication Journal: Research in Developmental Disabilities

Method: Online database searches and hand searches of journals in the field led to identify papers eligible for review. Assess these against predefined criteria and synthesise the findings.

Review question: What is the relationship between parental hope and psychological outcomes for parents who have a child with a disability?

PICOS

Participants of studies are parents or care givers of children who have a disability (physical, intellectual or developmental). Significant visual or hearing impairment is deemed as disabilities given the impact on the child and family functioning. At least one of the following parental psychological outcomes were measured: wellbeing, adjustment, adaption, stress or mental health (mood, depression, anxiety). Study design could be controlled, quasi-experimental, case study, small study or observational.

Eligibility Criteria:

- English language
- No date restriction
- Measured at least one of the following parental psychological outcomes: wellbeing, adjustment, adaption, stress or mental health (mood, depression,

anxiety) and investigated the relationship between hope and the psychological outcomes. Intervention studies were baseline data could be obtained are eligible for inclusion.

- Exclusion criteria: abstracts did not provide sufficient detail to make a decision about whether the inclusion criteria, abstract unavailable, conference proceedings, duplicate records. Qualitative studies (as focused on relationship between specific variables) or intervention studies were baseline data not available.
- Google Scholar used to trace alternative versions of abstracts

Information Sources:

- Ovid (Embase, Medline and PsyInfo)
- EBSCO (CINAHL, ERIC,)
- ProQuest (ASSIA, Social Services Abstracts and Sociological Abstracts)
- NCBI (PubMed)
- Hand searches of reference list of any review paper identified
- Hand searches of journals with most frequently citied sources of citations in the articles that met edibility criteria.

Literature Search Strategy

- Multi-database keyword search and topic/subject heading searches.
- Variations of: parent, mother/mum, father/dad, carer/ caregiver,
- And: disability/disabilities/disabled, developmental disabilities, mental deficiency, disabled person
- And: hope / hope theory

Study Selection

1. Initial screening of titles and abstracts if they meet eligibility criteria.
2. Full-text of articles deemed to meet the inclusion criteria for the review based on the abstract reviewed.

3. Those still meeting the inclusion criteria selected to be part of the final methodological review and appraisal.
4. Represent process as flow chart (PRISMA statement, Mother et al 2009)

Data extraction: (need to create standardised data extraction form)

- General (date of extraction, record number, author, article title, citation, type of publication, Country of origin, source of funding (if known).
- Study characteristics (Aim/objectives of study, design, inclusion criteria, exclusion criteria, recruitment procedures used, method, sampling, Limitations
- Participant characteristics (age, gender, ethnicity, socio-economic status, child disability / syndrome characteristics, co-morbidities, number of participants in sample)
- Intervention and setting (description of intervention and controls and setting)
- Outcome data/results (Units of assessment or measures used, Stats techniques used, Variables, length of follow-up/number of follow-up, number of participants approached, enrolled, included in analysis, withdrew/excluded/lost in follow-up, analysis, key results – overall/subgroup), adverse events

Quality Assessment:

- Develop tool assessing meeting inclusion criteria (based on SIGN, 2008, and York University's Centre for Reviews and Dissemination guidance for undertaking reviews in healthcare, CRD, 2009
- Quality criteria items across six dimension of quality
    - Research questions
    - Selection of participants
    - Assessment
    - Confounding variables
    - Statistical analysis
    - Quality of reporting

- Numerical ratings: 3 = well covered, 2 = adequately assessed, 1 = poorly covered, 0 = not addressed / not reported / not applicable (not relevant to the study design or article).
- Plus overall quality of the study (to avoid poor score on one index skewing the overall score of an otherwise good study. 3 = excellent, 2 = good, 1 = adequate, 0 = poor.
- Get independent scoring from second person.
- Assess inter-rater reliability (Cohen's Kappa).

Data synthesis:

- Summarise the study characteristics and findings for all studies chosen for final selection.
- Provide quality rating data for each domain and an overall description for studies.
- Narrative synthesis of results grouping, demographic data, presentation of hope and hope related to psychological outcomes.
- Report the limitations of literature and identify any gaps for future research.

Dissemination:

- Constituent part of portfolio thesis submitted to meet requirements of Doctorate in Clinical Psychology at the University of Edinburgh.
- Submit review for publication to the journal of Research in Developmental Disabilities.

Appendix C: Systematic review data extraction form

General Information			**Date**:
Author/s (year)			**Country of Origin**
Article Title			
Source of funding			
Study Characteristics		**Study design (cross-sectional/quantitative)**	
Aim/Objectives – present?			
Study inclusion / exclusion criteria reported?			
Recruitment method (online/postal/researcher)			**Self-selection?**
Population of sample (where recruited from)			**Overall no in sample**:
Participant characteristics (parents)	**Age** =	**Ethnicity** =	**Socio-economic status** =
Mothers (n) =	**Fathers** (n) =	Other (n) =	**Marital status** =
Child disability/syndrome characteristics / number			**Age (M, SD, r)** =
Child gender	male	female	**Co-morbidities of child dis reported** (yes/no)
No of participants	**Approached/asked to take part** (total & per group) =		**Included in analysis =**
	Enrolled / took part / returned responses =		**Withdrawals/exclusion/lost** =
(parental group/ child condition)	Group 1	Group 2	Group 3
Outcome data/results		**No of measures used**	
Variables Parents	**Measured by**:	**Child Measures**	
Hope	Trait / State Hope Scale	Adapted?	No
Stress		**Problem Behaviour**	
Anxiety / Worry		**Level of Disability**	

Mood / Depression		**Adaptive Behaviour**
Support		**Other:**
Quality of Life		
Other:		
Mean hope / SD / range		
Statistical techniques used =		**Power analysis**? y/n
Significant Correlations with hope		
Significant difference btw groups?	**Effect size**	
Significant Regression analysis predictors		
Results related to hope	Measurement tool or method used	
Summary of outcome data (relationship of hope with other psy variables- write – sig correlations, regressions etc)		
Group 1		
Group 2		
Group 3		
Additional relevant outcomes reported		
Limitations		

Appendix D: Systematic review quality appraisal tool

Rater: **Date:** **Author:** **Title:**

Variable	In this study this criterion is:		No
Research Question			
1. The study addresses an appropriate and clearly focused question.	Well covered (3) Adequately addressed (2) Poorly addressed (1)	Not addressed (0) Not reported (0) Not applicable (0)	
Selection of participants			
2. Participants recruited were a representative sample and bias was identified and minimised.	Well covered (3) Adequately addressed (2) Poorly addressed (1)	Not addressed (0) Not reported (0) Not applicable (0)	
3. A clear description of study recruitment methodology is included.	Well covered (3) Adequately addressed (2) Poorly addressed (1)	Not addressed (0) Not reported (0) Not applicable (0)	
4. Bias introduced with data collection was considered and minimised.	Well covered (3) Adequately addressed (2) Poorly addressed (1)	Not addressed (0) Not reported (0) Not applicable (0)	
5. The study indicated how many of the participants asked to take part did so, in each of the groups being studied.	Well covered (3) Adequately addressed (2) Poorly addressed (1)	Not addressed (0) Not reported (0) Not applicable (0)	
6. The nature and severity of the child's disability / impairment and child functioning is described.	Well covered (3) Adequately addressed (2) Poorly addressed (1)	Not addressed (0) Not reported (0) Not applicable (0)	
Assessment			
7. Relevant outcomes are measured in a standard, valid and reliable way.	Well covered (3) Adequately addressed (2) Poorly addressed (1)	Not addressed (0) Not reported (0) Not applicable (0)	
Confounding			
8. The main potential confounders are identified and taken into account in the design and analysis.	Well covered (3) Adequately addressed (2) Poorly addressed (1)	Not addressed (0) Not reported (0) Not applicable (0)	
Statistical Analysis			
9. Statistical analysis was fully reported and appropriate.	Well covered (3) Adequately addressed (2) Poorly addressed (1)	Not addressed (0) Not reported (0) Not applicable (0)	
Quality of reporting			
10. Detail of methodology, statistical analysis and results is sufficient to replicate.	Well covered (3) Adequately addressed (2) Poorly addressed (1)	Not addressed (0) Not reported (0) Not applicable (0)	
11. Generalizability of findings to similar groups.	Well covered (3) Adequately addressed (2) Poorly addressed (1)	Not addressed (0) Not reported (0) Not applicable (0)	
Total Score Descriptive category: Good 75%, Fair 74-50%, Weak <50%			

Appendix E: Journal of Intellectual Disability Research author guidelines (http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1365-2788/homepage/ForAuthors.html)

Author Guidelines

The journal to which you are submitting your manuscript employs a plagiarism detection system. By submitting your manuscript to this journal you accept that your manuscript may be screened for plagiarism against previously published works.

3.1. Getting Started

Content of Author Guidelines: 1. General, 2. Ethical Guidelines, 3. Submission of Manuscripts, 4. Manuscript Types Accepted, 5. Manuscript Format and Structure, 6. After Acceptance.

Relevant Documents: Colour Work Agreement Form

Useful Websites: Submission Site, Articles published in The Journal of Intellectual Disability Research, Author Services, Blackwell Publishing's Ethical Guidelines, Guidelines for Figures.

1. GENERAL

The Journal of Intellectual Disability Research is devoted exclusively to the scientific study of intellectual disability and publishes papers reporting original observations in this field. The subject matter is broad and includes, but is not restricted to, findings from biological, educational, genetic, medical, psychiatric, psychological and sociological studies, and ethical, philosophical, and legal contributions that increase knowledge on the treatment and prevention of intellectual disability and of associated impairments and disabilities, and/or inform public policy and practice. Such reviews will normally be by invitation. The Journal also publishes Full Reports,

Brief Reports, Letters to Editor, and an 'Hypothesis' papers. Submissions for Book Reviews and Announcements are also welcomed.

The Journal of Intellectual Disability Research will feature four Annotation articles each year covering a variety of topics of relevance to the main aims of the journal or topics. Senior researchers, academics and clinicians of recognised standing in their field will be invited to write an Annotation for the journal covering an area that will be negotiated with the Associate Editor, Prof. Chris Oliver, on behalf of the Editorial team. Anyone expert in his/her particular field wishing to submit an uninvited review is advised to seek prior guidance from the Associate Editor.

All papers are assessed by expert referees.

Please read the instructions below carefully for details on the submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication in The Journal of Intellectual Disability Research. Authors are encouraged to visit John Wiley & Sons Pte Ltd's Author Services for further information on the preparation and submission of articles and figures.

2. ETHICAL GUIDELINES

The Journal of Intellectual Disability Research adheres to the ethical guidelines for publication and research summarised below.

2.1. Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the Journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL must have critically reviewed its content and have approved the final version submitted for

publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship and, except in the case of complex large-scale or multi-centre research, the number of authors should not exceed six.

The Journal of Intellectual Disability Research adheres to the definition of authorship set up by The International Committee of Medical Journal Editors (ICMJE). According to the ICMJE authorship criteria should be based on 1) substantial contributions to conception and design of, or acquisition of data or analysis and interpretation of data, 2) drafting the article or revising it critically for important intellectual content and 3) final approval of the version to be published. Authors should meet conditions 1, 2 and 3.

It is a requirement that all authors have been accredited as appropriate upon submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

Acknowledgements: Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study and any potential conflict of interests if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

2.2. Ethical Approvals

Experimental Subjects: experimentation involving human subjects will only be published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 www.wma.net/e/policy/b3.htm) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant and according to the above

mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included. Editors reserve the right to reject papers if there are doubts as to whether appropriate procedures have been used.

All studies using human participants or animal subjects should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.

Ethics of investigation: Papers not in agreement with the guidelines of the Helsinki Declaration as revised in 1975 will not be accepted for publication.

2.3 Clinical Trials

Clinical trials should be reported using the CONSORT guidelines available at www.consort-statement.org. A CONSORT checklist should also be included in the submission material (http://www.consort-statement.org/mod_product/uploads/CONSORT 2001 checklist.doc).

Manuscripts reporting results from a clinical trial must provide the registration number and name of the clinical trial. Clinical trials can be registered in any of the following free, public clinical trials registries: www.clinicaltrials.gov, clinicaltrials-dev.ifpma.org/, isrctn.org/. The clinical trial registration number and name of the trial register will be published with the paper.

The Journal of Intellectual Disability Research encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public clinical trials registries: www.clinicaltrials.gov, clinicaltrials-dev.ifpma.org/, isrctn.org/. The clinical trial registration number and name of the trial register will then be published with the paper.

2.4 Conflict of Interest and Source of Funding

Conflict of Interest: Authors are required to disclose any possible conflict of interest. These include financial (for example patent, ownership, stock ownership, consultancies, speaker's fee). Author's conflict of interest (or information specifying the absence of conflicts of interest) will be published under a separate heading entitled 'Conflict of Interests'.

The Journal of Intellectual Disability Research requires that sources of institutional, private and corporate financial support for the work within the manuscript must be fully acknowledged, and any potential conflicts of interest noted. As of 1st March 2007, this information will be a requirement for all manuscripts submitted to the Journal and will be published in a highlighted box on the title page of the article. Please include this information under the separate headings of 'Source of Funding' and 'Conflict of Interest' at the end of your manuscript.

If the author does not include a conflict of interest statement in the manuscript then the following statement will be included by default: "No conflicts of interest have been declared".

Source of Funding: Authors are required to specify the source of funding for their research when submitting a paper. Suppliers of materials should be named and their location (town, state/county, country) included. The information will be disclosed in the published article.

2.5 Appeal of Decision

Authors who wish to appeal the decision on their submitted paper may do so by e-mailing the Editorial Office with a detailed explanation for why they find reasons to appeal the decision.

2.6 Permissions

If all or parts of previously published illustrations are used, permission must be obtained from the copyright holder concerned. It is the author's responsibility to obtain these in writing and provide copies to the Publishers.

2.7 Copyright Assignment

If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services; where via the Wiley Author Licensing Service (WALS) they will be able to complete the license agreement on behalf of all authors on the paper.

For authors signing the copyright transfer agreement

If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the Copyright FAQs below:

CTA Terms and Conditions

http://authorservices.wiley.com/bauthor/faqs_copyright.asp

2.8 OnlineOpen

If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons License Open Access Agreements (OAA):

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http://authorservices.wiley.com/bauthor/faqs_copyright.asp and visit

http://www.wileyopenaccess.com/details/content/12f25db4c87/Copyright--License.html.

If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) you will be given the opportunity to publish your article under a CC-BY license supporting you in complying with Wellcome Trust and Research Councils UK requirements. For more information on this policy and the Journal's compliant self-archiving policy please visit: http://www.wiley.com/go/funderstatement.

3. SUBMISSION OF MANUSCRIPTS

Manuscripts should be submitted electronically via the online submission site http://mc.manuscriptcentral.com/jidr. The use of an online submission and peer review site enables immediate distribution of manuscripts and consequentially speeds up the review process. It also allows authors to track the status of their own manuscripts. Complete instructions for submitting a paper are available online and below. Further assistance can be obtained from Ms Sue M Hampton-Matthews at the Editorial Office of JIDR, Second Floor, Douglas House, 18b Trumpington Road, Cambridge, CB2 2AH, UK +44 1223 746 124; e-mail: shm44@medschl.cam.ac.uk.

•Launch your web browser (supported browsers include Internet Explorer 6 or higher, Netscape 7.0, 7.1, or 7.2, Safari 1.2.4, or Firefox 1.0.4) and go to the journal's online Submission Site: http://mc.manuscriptcentral.com/jidr

•Log-in or click the 'Create Account' option if you are a first-time user.

•If you are creating a new account.

- After clicking on 'Create Account', enter your name and e-mail information and click 'Next'. Your e-mail information is very important.
- Enter your institution and address information as appropriate, and then click 'Next.'
- Enter a user ID and password of your choice (we recommend using your e-mail address as your user ID), and then select your area of expertise. Click 'Finish'.

•If you have an account, but have forgotten your log in details, go to Password Help on the journals online submission system http://mcv3support.custhelp.com and enter your e-mail address. The system will send you an automatic user ID and a new temporary password.

•Log-in and select 'Author Center'.

3.2. Submitting Your Manuscript

•After you have logged in, click the 'Submit a Manuscript' link in the menu bar.

•Enter data and answer questions as appropriate. You may copy and paste directly from your manuscript and you may upload your pre-prepared covering letter.

•Click the 'Next' button on each screen to save your work and advance to the next screen.

•You are required to upload your files.

- Click on the 'Browse' button and locate the file on your computer.
- Select the designation of each file in the drop-down menu next to the Browse button.
- When you have selected all files you wish to upload, click the 'Upload Files' button.

•Review your submission (in HTML and PDF format) before sending to the Journal. Click the 'Submit' button when you are finished reviewing.

3.3. Manuscript Files Accepted

Manuscripts should be uploaded as Word (.doc) or Rich Text Format (.rft) files (not write-protected) plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing. The files will be automatically converted to HTML and PDF on upload and will be used for the review process. The text file must contain the entire manuscript including title page, abstract, text, references, tables, and figure legends, but no embedded figures. Figure tags should be included in the file. Manuscripts should be formatted as described in the Author Guidelines below.

Please note that any manuscripts uploaded as Word 2007 (.docx) will be automatically rejected. Please save any .docx file as .doc before uploading.

3.4. Blinded Review

All manuscripts submitted to The Journal of Intellectual Disability Research will be reviewed by two experts in the field. The Journal of Intellectual Disability Research uses double-blinded review. The names of the reviewers will thus not be disclosed to the author submitting a paper and the name(s) of the author(s) will not be disclosed to the reviewers.

To allow double-blinded review, please submit (upload) your main manuscript and title page as separate files.

Please upload:

•Your manuscript without title page under the file designation 'main document'

•Figure files under the file designation 'figures'

•The title page, Acknowledgements and Conflict of Interest Statement where applicable, should be uploaded under the file designation 'title page'.

All documents uploaded under the file designation 'title page' will not be viewable in the HTML and PDF format you are asked to review at the end of the submission process. The files viewable in the HTML and PDF format are the files available to the reviewer in the review process.

3.5. Suggest a Reviewer

The Journal of Intellectual Disability Research attempts to keep the review process as short as possible to enable rapid publication of new scientific data. In order to facilitate this process, please suggest the names and current e-mail addresses of 1 potential international reviewer whom you consider capable of reviewing your manuscript. In addition to your choice the journal editor will choose one or two reviewers as well.

3.6. Suspension of Submission Mid-way in the Submission Process

You may suspend a submission at any phase before clicking the 'Submit' button and save it to submit later. The manuscript can then be located under 'Unsubmitted Manuscripts' and you can click on 'Continue Submission' to continue your submission when you choose to.

3.7. E-mail Confirmation of Submission

After submission you will receive an e-mail to confirm receipt of your manuscript. If you do not receive the confirmation e-mail after 24 hours, please check your e-mail address carefully in the system. If the e-mail address is correct please contact your IT department. The error may be caused by spam filtering software on your e-mail server. Also, the e-mails should be received if the IT department adds our e-mail server (uranus.scholarone.com) to their whitelist.

3.8. Manuscript Status

You can access ScholarOne Manuscripts any time to check your 'Author Center' for the status of your manuscript. The Journal will inform you by e-mail once a decision has been made.

3.9. Submission of Revised Manuscripts

Revised manuscripts must be uploaded within 3 months of authors being notified of conditional acceptance pending satisfactory revision. Locate your manuscript under 'Manuscripts with Decisions' and click on 'Submit a Revision' to submit your revised manuscript. Please remember to delete any old files uploaded when you upload your revised manuscript. Please also remember to upload your manuscript document separate from your title page.

4. MANUSCRIPT TYPES ACCEPTED

Original Research Article The main text should proceed through sections of Abstract, Introduction, Methods, Results, and Discussion.

Full Reports of up to 4,500 words are suitable for major studies, integrative reviews and presentation of related research projects or longitudinal enquiry of major theoretical and/or empirical conditions.

Brief Reports of up to 1,500 words are encouraged especially for replication studies, methodological research and technical contributions.

Annotation Articles should be no more than 5,500 words long including tables and figures and should not have been previously published or currently under review with another journal. The normal instructions to authors apply. The date for submission of the article should be negotiated with the Associate Editor. An honorarium of £400 in total shall be paid to the authors(s) when the article is accepted for publication.

Three main types of Annotations will be commissioned: 1. Authoritative reviews of empirical and theoretical literature. 2. Articles proposing a novel or modified theory or model. 3. Articles detailing a critical evaluation and summary of literature pertaining to the treatment of a specific disorder.

A Hypothesis Paper can be up to 2,500 words and no more than twenty key references. It aims to outline a significant advance in thinking that is testable and which challenges previously held concepts and theoretical perspectives.

5. MANUSCRIPT FORMAT AND STRUCTURE

5.1. Format

Language: The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english_language.asp . All services are

paid for and arranged by the author and use of one of these services does not guarantee acceptance or preference for publication.

Abbreviations, Symbols and Nomenclature: Spelling should conform to The Concise Oxford Dictionary of Current English and units of measurements, symbols and abbreviations with those in Units, Symbols and Abbreviations (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of SI units.

It is important that the term 'intellectual disabilities' is used when preparing manuscripts.

Please note that 'intellectual disability', as used in the Journal, includes those conditions labelled mental deficiency, mental handicap, learning disability and mental retardation in some counties.

5.2. Structure

All manuscripts submitted to The Journal of Intellectual Disability Research should include: Title, Keywords, structured Abstract, Main Text (divided by appropriate sub headings) and References.

Title Page: Please remember that peer-review is double-blind, so that neither authors nor reviewers know each other's' identity. Therefore, no identifying details of the authors or their institutions must appear in the submitted manuscript; author details should be entered as part of the online submission process. However, a 'Title Page' must be submitted as part of the submission process as a 'Supplementary File Not for Review'. This should contain the title of the paper, names and qualifications of all authors, their affiliations and full mailing address, including e-mail addresses and fax and telephone numbers.

Keywords: The author should also provide up to six keywords to aid indexing.

Abstracts: For full and brief reports a structured summary should be included at the beginning of each article, incorporating the following headings: Background, Method, Results, and Conclusions. These should outline the questions investigated, the design, essential findings, and the main conclusions of the study.

Optimizing Your Abstract for Search Engines: Many students and researchers looking for information online will use search engines such as Google, Yahoo or similar. By optimizing your article for search engines, you will increase the chance of someone finding it. This in turn will make it more likely to be viewed and/or cited in another work. We have compiled these guidelines to enable you to maximize the web-friendliness of the most public part of your article.

5.3. References

The Journal follows the Harvard reference style. References in text with more than two authors should be abbreviated to (Brown et al. 1977). Authors are responsible for the accuracy of their references.

The reference list should be in alphabetical order thus:

•Giblett E.R. (1969) Genetic Markers in Human Blood.

•Blackwell Scientific Publications, Oxford.

•Moss T.J. & Austin G.E. (1980) Preatherosclerotic lesions in Down's syndrome. Journal of Mental Deficiency Research 24, 137- 41.

•Seltzer M. M. & Krauss M.W. (1994) Aging parents with co-resident adult children: the impact of lifelong caregiving. In: Life Course Perspectives on Adulthood and Old Age (eds M. M. Seltzer, M.W. Krauss & M. P. Janicki), pp. 3–18. American Association on Mental Retardation, Washington, DC.

Where more than six authors are listed for a reference please use the first six then 'et al.'

The Editor and Publisher recommend that citation of online published papers and other material should be done via a DOI (digital object identifier), which all reputable online published material should have - see www.doi.org/ for more information. If an author cites anything which does not have a DOI they run the risk of the cited material not being traceable.

We recommend the use of a tool such as EndNote or Reference Manager for reference management and formatting.

EndNote reference styles can be searched for here:
www.endnote.com/support/enstyles.asp

Reference Manager reference styles can be searched for here:
www.refman.com/support/rmstyles.asp

5.4. Tables, Figures

Tables: Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, Table 2, etc., and give a short caption.

Figures: All graphs, drawings and photographs are considered figures and should be numbered in sequence with Arabic numerals. All symbols and abbreviations should be clearly explained.

Tables and figures should be referred to in the text together with an indication of their approximate position recorded in the text margin.

Preparation of Electronic Figure for Publication

Although low quality images are adequate for review purposes, print publication requires high quality images to prevent the final product being blurred or fuzzy. Submit EPS (line art) or TIFF (halftone/photographs) files only. MS PowerPoint and Word Graphics are unsuitable for printed pictures. Do not use pixel-oriented programmes. Scans (TIFF only) should have a resolution of at least 300 dpi (halftone) or 600 to 1200 dpi (line drawings) in relation to the reproduction size (see below). Please submit the data for figures in black and white or submit a Colour Work Agreement Form (see Colour Charges below). EPS files should be saved with fonts embedded (and with a TIFF preview if possible).

For scanned images, the scanning resolution (at final image size) should be as follows to ensure good reproduction: line art: >600 dpi; halftones (including gel photographs): >300 dpi; figures containing both halftone and line mages: >600 dpi.

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Check your electronic artwork before submitting it:
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Appendix F: Ethical approval

School of Health in Social Science
Clinical Psychology

The University of Edinburgh
Medical School
Doorway 6, Teviot Place
Edinburgh EH8 9AG

Telephone 0131 651 3969
Fax 0131 650 3891
Email submitting.ethics@ed.ac.uk

04 December 2013

Dear Louise,

Application for Level 2 Approval

Re: The Parenting Game – a Behavioural Challenge: Exploring the use of an online game-informed learning activity on challenging behaviour, as an intervention for parents of children with an Intellectual Disability.

Thank you for submitting the above research project for review by the Section of Clinical Psychology Ethics Research Panel. I can confirm that the submission has been independently reviewed and was approved on the 21st November 2013.

Should there be any change to the research protocol it is important that you alert us to this as this may necessitate further review.

Yours sincerely,

Kirsty Gardner

Secretary
Clinical Psychology

Appendix G: Measured used in main thesis study

State Hope for the Child Scale:

Read each item carefully. Using the scale shown below, please select the answer that best describes how you think about yourself right now. Please take a few moments to focus yourself and what is going on in your life at this moment. Once you have this **"here and now"** mind set, please answer each item.

	Read each item carefully and select the answer that best describes how much you agree with each statement							
	1 Definitely false	**2 Mostly false**	**3 Somewhat false**	**4 Slightly false**	**5 Slightly true**	**6 Somewhat true**	**7 Mostly true**	**8 Definitely true**
a. If I should find my child in a jam (difficulty), I could think of many ways to get out of it.	○	○	○	○	○	○	○	○
b. At the present time, I am energetically pursuing my goals for my child.	○	○	○	○	○	○	○	○
c. There are lots of ways around any problem my child has.	○	○	○	○	○	○	○	○
d. Right now, I see myself as being pretty successful as a parent.	○	○	○	○	○	○	○	○
e. I can think of many ways to reach my current goals for my child.	○	○	○	○	○	○	○	○
f. At this time, I am meeting the goals that I have set for my child.	○	○	○	○	○	○	○	○

Parental Locus of Control Scale (Campis et al., 1986)

Subscales: Child's Control of Parent's Life and Parental Control of Child's Behaviour.

	Please indicate whether you agree or disagree with each statement by answering yes or no	
	Yes	**No**
a. My life is chiefly controlled by my child.		
b. I always feel in control when it comes to my child.		
c. My child does not control my life.		
d. My child's behaviour is sometimes more than I can handle.		
e. My child influences the number of friends I have.		
f. Sometimes I feel that my child's behaviour is hopeless.		

g. I feel like what happens in my life is mostly determined by my child.		
h. It is often easier to let my child have his/her own way than to put up with a tantrum.		
i. It is easy for me to avoid and function independently of my child's attempts to have control over me.		
j. I find that sometimes my child can get me to do things I really did not want to do.		
k. When I make a mistake with my child I am usually able to correct it.		
l. My child often behaves in a manner very different from the way I would want him / her to behave.		

The Behavior Problems Inventory for Individuals with Intellectual Disabilities - Short Form (Rojahn et al., 2012a)

Instructions

Below are broad definitions followed by specific types of behaviour problems: Self-injurious behaviours, aggressive/destructive behaviours and stereotyped behaviours.

Please indicate which behaviours you have observed during the past **two months** by selecting the appropriate box for **how often** a described behaviour typically occurs and **how serious** a problem the behaviour is. If the behaviour has not occurred during the past two months and therefore poses no problem check "never/no problem".

Self-injurious behaviour

Self-injurious behaviour causes damage to the person's own body; i.e. damage has either already occurred, or it must be expected if the behaviour remains untreated. Self-injurious behaviours occur repeatedly in the same way over and over again, and they are characteristic for that person.

Mild Problem
Behaviour occurs but does not inflict significant damage on the individual (e.g., temporary reddening of the skin, very light bruising).

Moderate Problem
Behaviour may inflict moderate damage on the individual (e.g., moderate bruising, scratching through the skin, repeatedly picking scabs).

Severe Problem
Behaviour may inflict moderate to severe damage on the individual (e.g. biting through the skin, eye gouging, fracturing bones) minor or major medical intervention required.

21. Please rate the frequency and severity of each behaviour using the guidance above. If a behaviour is not a problem then please select Never/No Problem for both frequency and severity.

	Average Frequency of Occurrence					Severity of the Problem			
	Never / No problem	**Monthly**	**Weekly**	**Daily**	**Hourly**	**Never/No problem**	**Mild**	**Moderate**	**Severe**
a. Self-biting	○	○	○	○	○	○	○	○	○
b. Head hitting	○	○	○	○	○	○	○	○	○
c. Body hitting (except for the head) with own hand or with any other body part	○	○	○	○	○	○	○	○	○
d. Self-scratching	○	○	○	○	○	○	○	○	○
e. Pica (ingesting non-food items)	○	○	○	○	○	○	○	○	○
f. Inserting objects in nose, ears, anus, etc.	○	○	○	○	○	○	○	○	○
g. Hair pulling (tearing out patches of hair)	○	○	○	○	○	○	○	○	○
h. Teeth grinding (evidence of ground teeth)	○	○	○	○	○	○	○	○	○

Aggressive/Destructive behaviours

Aggressive or destructive behaviours are deliberate overt attacks directed towards other individuals or property.

Mild Problem
Behaviour occurs but does not inflict significant damage on other people (e.g., temporary reddening of the skin, very light bruising); or disruption or mild damage to property (e.g., objects thrown, furniture tipped, doors slammed, meals spoiled, paint scratched). Item does not require repair or replacement.

Moderate Problem
The behaviour may inflict moderate damage on other people (e.g., moderate bruising, scratching through the skin, repeatedly picking scabs); or moderate damage to property (e.g., curtains torn, furniture partly broken). Item requires repair but can be used.

Severe Problem
The behaviour may inflict moderate to severe damage on other people (e.g., biting through the skin, eye gouging, fracturing bones) minor or major medical intervention required; or significant damage to property. Item requires repair and cannot be used.

22. Please rate the frequency and severity of each behaviour using the guidance above. If a behaviour is not a problem then please select Never/No Problem for both frequency and severity.

	Average Frequency of Occurrence					Severity of the Problem			
	Never/no problem	**Monthly**	**Weekly**	**Daily**	**Hourly**	**Never/No problem**	**Mild**	**Moderate**	**Severe**
a. Hitting others	○	○	○	○	○	○	○	○	○
b. Kicking others	○	○	○	○	○	○	○	○	○
c. Pushing others	○	○	○	○	○	○	○	○	○
d. Biting others	○	○	○	○	○	○	○	○	○
e. Grabbing and pulling others	○	○	○	○	○	○	○	○	○
f. Scratching others	○	○	○	○	○	○	○	○	○
g. Pinching others	○	○	○	○	○	○	○	○	○
h. Verbally abusive with others	○	○	○	○	○	○	○	○	○
i. Destroying things (e.g., rips clothes, throws chairs, smashes tables)	○	○	○	○	○	○	○	○	○
j. Bullying - being mean or cruel (e.g., grabbing toys or food from others)	○	○	○	○	○	○	○	○	○

Stereotyped behaviours

Stereotyped behaviours look unusual, strange, or inappropriate to the average person. They are voluntary acts that occur repeatedly in the same way over and over again, and they are characteristic for that person. However, they do NOT cause physical damage.

23. Please rate the frequency of each behaviour. There is no severity rating for these behaviours.

	Average frequency of Occurrence				
	Never/no problem	**Monthly**	**Weekly**	**Daily**	**Hourly**
a. Rocking, repetitive body movements	○	○	○	○	○
b. Sniffing objects, own body	○	○	○	○	○
c. Waving or shaking arms	○	○	○	○	○
d. Manipulating (e.g., twirling, spinning) objects	○	○	○	○	○
e. Repetitive hand and/or finger movements	○	○	○	○	○
f. Yelling and screaming	○	○	○	○	○
g. Pacing, jumping, bouncing, running	○	○	○	○	○
h. Rubbing self	○	○	○	○	○
i. Gazing at hands or objects	○	○	○	○	○
j. Bizarre body postures	○	○	○	○	○
k. Clapping hands	○	○	○	○	○
l. Grimacing	○	○	○	○	○

Knowledge of Behavioural Principles Questionnaire

Please answer whether you think the following statements are true or false.

	True	False
a. Modelling or demonstrating appropriate behaviour is a good way to support new learning for children with a Learning Disability.	○	○
b. Challenging behaviour is generally unrelated to infection or illness in children with a Learning Disability.	○	○
c. Extinction of a behaviour means that it is no longer being reinforced and will therefore gradually stop.	○	○
d. It is important to spend lots of time when explaining to children with a Learning Disability what will happen if they do not stop a behaviour.	○	○
e. It is important to put in reprimands for children with a Learning Disability, such as time out or "the naughty step".	○	○
f. When talking about managing behaviour, A-B-C means Antecedent - Behaviour - Consequence.	○	○
g. When a child with a Learning Disability is presenting with challenging behaviour, a good strategy is to ignore the child until they stop the socially inappropriate behaviour and then engage with them.	○	○
h. Reinforcement is something that occurs after a behaviour which means the behaviour is more likely to happen in the future.	○	○
i. A visual timetable can often help reduce challenging behaviour.	○	○
j. Behaviour is often due to naughtiness for children with a Learning Disability.	○	○
k. An extinction burst occurs when a behaviour has become more challenging.	○	○
l. Behaviour is often a form of communication for children with a Learning Disability.	○	○
m. An extinction burst can occur suddenly for no reason.	○	○
n. Challenging behaviour is generally nothing to do with the environment or situation.	○	○
o. Ignore-distract-redirect is a planned way of managing challenging behaviour.	○	○
p. Reinforcement is a planned activity carried out by people supporting a child.	○	○
q. Negative reinforcement is giving things to the child they do not want, e.g. chores.	○	○
r. Reinforcement of a behaviour produces socially appropriate results.	○	○
s. Positive reinforcement occurs when something is given or added after a behaviour.	○	○

Appendix H: List of organisations contact to host project

Action for Children
Autism Cornwall
bristolparentcarers.org.uk
British Institute of Learning Disability
Capability Scotland
Caudwell kids WM
Cerebra
Challenging behaviour foundation
Disabled Living Foundation
DLF (Disabled Living Foundation)
Down's syndrome Scotland
East Sussex Parent and Carers Council
Enable Scotland
Every disabled child matters
Families United
Family Footings
Family Fund
Family voice
Focus on Disability
Follow your dreams
Foundation for People with Learning Disabilities
Full of life
G.D.D Awareness
Home Start
Inspired Parents
Kindred
LD today
Learning Disability Wales
LF Carers community
Love Disability
Mencap
Mumsnet
Netbuddy
PAMIS
Parents for Change
Pass it on Parents
PBS Chat
pencru.org
PIPS Stocksport's carer forum
Progress magazine
Rett UK
Reverse Retts
Scope

Scottish Consortium for Learning Disability

Share Scotland

Sheffield Parent Carer Forum

Shine UK

Shropshire PACC

Smith-Magenis UK

Special Kids in the UK

Special Needs Kids

Special Needs Parents Association

SWAN

The Action Group

The Children's Trust

The Learning Disability Elf

The Rett Syndrome Research Trust

The special educational consortium

Tizard Canter

Unique

Voice Ability

Voice of carers Across Lothian (VOCAL)

WF parent forum

Appendix I: Participant information sheet and consent form

Information on the project and research

Dear Parent/Carer,

I work with children and young people with a Learning Disability and their families. This means children and young people who:

• are under the age of 18

• and have a significant difficulty with intellectual functioning

• and have a significant difficulty with daily living skills.

Some of these individuals may also have other diagnoses such as Down syndrome or autism spectrum disorder.

The family of these children and young people may have to manage lots of different behaviours. Some of these behaviours may be a challenge for carers and the individuals themselves, for example self-harm or repetitive activities. I would like to know more about how online materials and learning can help parents understand and manage these behaviours.

My research project provides information and strategies aiming to help parents think about:

• Common reasons behind behaviours

• Why some behaviours might continue

• Some strategies to manage behaviour

The project starts with a short survey about you and your child. Next, you are presented with information and strategies to help manage behaviours that challenge. Then, you will be asked some more questions to measure how helpful this information has been. In total, it should take about an hour to complete. I am really interested in what you, as parents, think. Therefore space is provided for your comments and feedback. There will also be an option to provide your email address

to allow me to make contact for a brief follow-up assessment one month after completing the survey.

Caring for a child or young person with a learning disability can have both positive and negative aspects. Some of the questions may make you feel or think about things that are difficult and upsetting. If any concerns are raised about the nature of your child's behaviour please contact your GP or other professionals involved in the care of your child.

I would be very grateful if you would complete this online activity as part of my research. This project has gained ethical approval from the School of Health and Social Science at the University of Edinburgh, and is supervised by Dr Hannah MacLean (NHS Lothian) and Dr Dougal Hare (University of Edinburgh). I am happy to receive responses from more than one parent or carer thinking about the same child. Please encourage other parents or carers of children with a Learning Disability to consider taking part in this research.

Thank you for your time,

Louise McCool
Trainee Clinical Psychologist
School of Health in Social Science, University of Edinburgh, Old Medical School, Teviot Place, Edinburgh, EH8 9AG
Email: informationonbehaviour@gmail.com
(Unfortunately I am only able to reply to queries about the project only.)

Frequently asked questions

What are the possible benefits of taking part?

You may find new information and helpful strategies to increase your

understanding and management of your own child's behaviour. This research project also aims to see if online materials are useful to parents waiting for help from specialist services or for those who are struggling with difficulties but who do not want to access services. Information gained from carrying out this research may help improve the treatment options offered to families.

What are the possible disadvantages and risks of taking part?

Taking part in this study will require a time commitment of about an hour. There is no obvious risk to you in taking part. However, if concerns are raised about your own child by behaviours described within the study please contact your GP, or other professionals involved in your child's care, to discuss these.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you decide to take part, you are still free to withdraw at any time and without giving any reason. Your decision to take part will not affect your involvement with any website or online forum.

What will happen to the information I provide?

The information will be kept anonymous, stored securely and used only for the purpose of this research. The overall findings will be written up for publication and shared with other researchers and professionals to help improve services for children and young people with a Learning Disability. No information collected will be used to identify you or your family.

If you provide an email address to take part in the follow-up component of this study it will not be passed onto third parties and will be deleted at the end of the follow-up period.

How will I find out the results of the study?

Information on the overall results of the study will be emailed to participants who

have provided a contact email address and will also be posted on to the relevant internet sites who took part. Individual results will not be identifiable.

If you have any further questions about the study please contact me on:
informationonbehaviour@gmail.com
(Unfortunately I am only able to reply to queries about the project only.)

Consent Form

To comply with ethical guidelines and participate in this research you must decide whether you agree with each of the statements below. If you need further information please contact me on informationonbehaviour@gmail.com or return to the 'Information on Research' page.

1. I confirm that I have read and understand the information on the research project and have had sufficient time to decide whether to take part in this study.

Yes, I agree.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my input to this website / online forum or legal rights being affected.

Yes, I agree.

3. I give my informed consent to take part in the above study and for my responses to be used for the purposes of this research.

Yes, I agree.

To take part

As this is a research project to support parents of children with a learning disability please confirm the following:

4. I currently am a parent or care-giver for child with a Learning Disability.

Yes

5. I am over 16 years old.

Yes